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Regulating Physician-Negotiated Death

A.Klijn, F. Mortier, M. Trappenburg, M. Otłowski (editors)

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INTRODUCTION

A Comparative Analysis of Euthanasia Regimes

Introduction to the Issue

Albert Klijn, Margaret Otlowski, Margo Trappenburg

In July 2001 the Human Rights Committee, established to safeguard the rights laid down in the International Covenant on Civil and Political Rights, addressed itself to the human rights situation in the Kingdom of the Netherlands. Among other concerns, the Committee raised some questions about the situation regarding euthanasia and assisted suicide. The new Dutch law on euthanasia states that under certain conditions a physician is not criminally liable when he or she terminates the life of a person on the 'voluntary and well-considered request of the patient', in a situation of 'unbearable suffering' offering 'no prospect of improvement'. The Committee wanted to know exactly what is meant by the terms a 'voluntary well-considered request', 'unbearable suffering' and 'no prospect of improvement'. It urged the Dutch government to provide detailed information about the application of these criteria in its next report. Moreover, the Committee expressed doubts about the control system. Would the assessment committees which are supposed to evaluate cases of euthanasia be scrupulous enough? Would the legalisation of euthanasia and physician-assisted suicide in the long run lead to routinisation and insensitivity and to unintended, unanticipated consequences?¹ In response to these concerns and allegations, the Dutch Minister of Health announced that she would take the questions into serious consideration and answer them in due time in a formal government report.

In a way, one might read this special issue of *Recht der Werkelijkheid* as a preliminary study for the next report of the Dutch government to the Human Rights Committee. Significantly, however, quite independently of this recent call from the Human Rights Committee for further explanation of the Dutch position on euthanasia, there has been ongoing research activity in the Netherlands directed to end of life issues. This is due to the fact that the Dutch are generally open and fair-minded and are themselves interested in getting to the bottom of these issues. There is a genuine search in this country for sound and effective solutions to the problems inherent in the legalisation of euthanasia and they have not waited to be asked to provide detailed research and ultimately an account of the Dutch position.

¹ Concluding observations of the Human Rights Committee: Netherlands, 20/07/2001. CCPR/CO/72/NET.

We would not wish to pretend that the Dutch approach to the regulation of euthanasia is perfect. We do believe, however, that an objective evaluation of the Dutch position requires consideration of what is happening in other countries with regard to euthanasia. This may lead us to the conclusion that although the Dutch situation may not be perfect, many things seem to be much worse in other parts of the world.² In common law countries (the US, Canada, Australia) euthanasia is still strictly forbidden. But that does not mean that physicians never take their patients' lives. Empirical evidence suggests that medical help in dying also occurs in these countries, but that this never is reported or assessed, as it is in the Netherlands. Nor are physicians who perform euthanasia prosecuted. The evidence even suggests that there are more physician-assisted deaths that were not requested by or even discussed with the suffering patient in countries where euthanasia is strictly forbidden, as Otłowski argues in this issue. In Belgium, where euthanasia is still illegal, research regarding medical decisions concerning the end of life shows that physicians relatively often take such decisions without consulting the patient. In fact, as the articles by Adams and Mortier show, this was one of the main reasons why the Belgian parliament decided to enact a euthanasia bill similar to the one adopted in the Netherlands. In the United States governmental authorities, both at the federal and state level, have tried to maintain the taboo on physician aid in dying. According to Battin, one of the consequences of this policy seems to have been that proponents of euthanasia now advocate a do-it-yourself strategy, involving helium tanks, plastic bags, and suicide handbooks. It seems not unlikely that even many opponents of euthanasia, given the choice between the doctor-focused approach in the Netherlands and the self-help strategy encouraged by the American prohibition, would prefer to go the Dutch way.

The article by Vezzoni deals with the practice of so-called advance directives in many different countries. In an advance directive, a patient can indicate what he would like physicians to do, should he become permanently comatose, senile or otherwise mentally incompetent. For patients, and future patients, advance directives can be an important means of communication with physicians and hospitals. The data presented by Vezzoni indicate that the Netherlands is one of the few countries where the autonomy of the patient is treated as fundamental to the doctor-patient relationships and the wishes expressed in advance directives are legally binding on doctors.

As Weyers shows, the Dutch certainly did not adopt their legislation overnight. The legislation which has ultimately been adopted seems to be what the Dutch people want. From the research reported by Trappenburg and Van Holsteyn we may infer that the Dutch seem to know what they mean when they talk about soft or vague criteria in the law, such as 'unbearable suffering'. As Klijn argues, the Dutch know that their system of control is imperfect and must

2 Cf. Griffiths, J., 'Euthanasia and Human Rights', Newsletter MBPSL (forthcoming). Go to www.rechten.rug.nl/mbpsl/mbpsl_newsletter.

be improved. And there are many researchers like Schwitters, who repeatedly remind them of the dangers of their policy of openness and transparency.

Although this collection of papers may prove useful in responding to the Human Rights Committee, assisting the Dutch government in its reporting obligations was not our common intention when we started to collaborate in producing this special Issue. Our main motive was, obviously, the widening of our knowledge with regard to end-of-life decision making. Above all, the Issue is meant to present a comparative analysis of euthanasia regimes.

The first section provides us with some historical insight into the processes of legal change. The articles of Weyers, Adams and Battin deal respectively with the way legal regulation of euthanasia did or did not come about in the Netherlands, Belgium and the United States. In the US, the adversarial legal culture and the political polarization seem to inhibit useful regulation. The legislation adopted in the Netherlands may be seen as the final codification of norms and rules that have been developed by the medical profession and the courts over twenty-five years. In contrast, the Belgian law seems to be a creation of the political elites and will, more or less, be imposed on the medical profession. This crucial difference between the Dutch law on the one hand, and the Belgian law on the other, may have significant implications when it comes to implementation and control in the Belgian context.

The second section is focused on the issue of regulation. Vezzoni presents new comparative data on living wills (advance directives), indicating that the legal status of advance directives differs in different countries and different legal cultures. In comparative discussions of legal regimes governing end-of-life decision making the 'slippery slope' argument frequently arises, namely that a legal regime which permits euthanasia is bound to deteriorate. Schwitters argues that there is an element of truth in these arguments. According to his reasoning, the Dutch tendency to strive for transparency with regard to every possible case of euthanasia carries certain dangers. In an attempt to avoid hidden practices one may end up legalizing and accepting more than one had intended. The article by Trappenburg and Van Holsteyn can be read as an attempt to work out what Dutch citizens meant to legalize when they (or rather their chosen representatives) accepted the present euthanasia law. Did they intend to accept every possible request for euthanasia, provided it was well-considered? Or do they want to restrict euthanasia to clear cases of unbearable suffering due to serious diseases? Trappenburg and Van Holsteyn present new data based on extensive opinion surveys. From their findings, it is quite obvious that there are clear limits to the Dutch acceptance of euthanasia. While the articles in this section together provide an interesting comparative view, there is still much work that remains to be done. Some of it will be done in the very near future as is outlined in the research note by Van der Heide, Onwuteaka-Philipsen, Van der Maas and Van der Wal, who intend to carry out extensive comparative research on end-of-life decision making in six European coun-

tries. Once completed, this research will undoubtedly shed further light on many of these issues.

Our third section focuses more specifically on the effectiveness in practice of attempts to control euthanasia through prohibition or some other form of regulatory system. Otłowski describes and analyses how end-of-life decision-making is dealt with in common law countries where euthanasia is prohibited and seeks to highlight the fallacy in the assumption that prohibition of euthanasia is the same thing as to 'control' of the practice. Klijn examines the Dutch position in relation to the consultation and notification requirements which doctors practicing euthanasia must comply with and suggests a way to measure norm compliance with regard to the euthanasia notification procedure in the Netherlands. He is cautiously optimistic, especially because of the explicit policy of the control agencies to respect doctors' needs for legal security enhancing mutual trust. Deliens and Mortier show that norm compliance and norm acceptance in Belgium will probably be much more problematic, particularly in view of the fact that in Belgium, the laws have been developed by the legislature with very little input from the medical profession.

The question might be raised why this special Issue, of a Dutch language journal, most of whose contributors are Dutch researchers, has been published in English. The decision to do this emerged from the sense that the Dutch experience with euthanasia is not only of interest to the Dutch themselves. For many years now, the Netherlands has been the focus of international attention with regard to its approach to euthanasia, and as pressure for legalisation of euthanasia mounts in other jurisdictions, there has been keen interest abroad in gauging the Dutch the experience in practice. Unfortunately, not all countries have the same interest in examining end-of-life practices and evaluating the effectiveness of their laws. Indeed, the assumption that countries which prohibit euthanasia are thereby dealing effectively with it, usually takes the place of careful investigations. Conversely, there has also been much misinformation and unsubstantiated allegations of abuse about the practice of euthanasia in the Netherlands. For these reasons, it is very important that an objective and scholarly assessment of the Dutch position, and how it stands in comparison to other jurisdictions which prohibit euthanasia, is published in a language that is widely accessible in order to help inform the debate internationally on the subject of euthanasia.

This brings us to another important proposition: an approach which may operate with relative success in the Netherlands is not necessarily 'exportable' to other countries. It is important in this regard for the Dutch policy on euthanasia to be understood in the context of the complex health care, legal and cultural environment in which it has developed. As Griffiths makes clear in his conclusion, the most important factor in the Dutch legal development seems to be the medical profession's participation in the process. Such participation, however, is not a commodity easy to transplant and as Deliens and Mortier

suggest, its absence in the Belgian context may well prove to be problematic in the implementation of and enforcement of euthanasia in that jurisdiction.

In closing, some words on the process by which this Issue came into being. Most of the articles were first presented as papers at the July 2001 meeting of the Law and Society Association in Budapest. The authors who presented their papers at this conference benefited from the discussions in the two panels on end-of-life decision making, the contributions of other presenters, and the comments of other researchers in the audience. In the course of preparing the papers for this special Issue, there has been a further process of review, comment and constructive criticism amongst the contributors. This has been undertaken in the true spirit of mutual respect and co-operation.

We close in expressing explicitly our gratitude to the Netherlands Scientific Organisation (NWO)/SaRO for their financial support and to Hannie van de Put, the secretary of the Journal, for her endless, careful technical assistance in producing this Issue.

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LEGAL CHANGE

Euthanasia: The process of legal change in the Netherlands

The making of the 'requirements of careful practice'

Heleen Weyers

1. Introduction

The process of legal change with regard to euthanasia in the Netherlands began with public debates on the issue in the 1970s, and ended – at least for the time being – when the *Law on Termination of Life on Request and Assisting Suicide (Review Procedures)* was approved by the Dutch Parliament in 2001. The present article describes this process of legal change in terms of the interplay of the various social actors who contributed to the making of the 'requirements of careful practice' – the judiciary, the medical profession, pressure groups, legal scholars and Parliament. Dealing with each of their contributions in turn allows me – by two *Intermezzi* so to speak – to touch upon two secondary themes. The first highlights the unusual role played by the Royal Dutch Medical Association (KNMG) in the process. Its strategy may be explained by examining features of the Dutch elite and the Association's recent history. The second unravels a popular misconception regarding the so-called 'policy of forbearance' in the Netherlands.¹

2. Legal Background

Three articles of the Dutch Criminal Code are of particular importance in connection with euthanasia and assisting suicide: articles 40, 293 and 294.

Article 40 states: A person who commits an offence as a result of a force he could not be expected to resist [*overmacht*] is not criminally liable.

Article 293: A person who takes the life of another person at that other person's express and earnest request is liable to a term of imprisonment of not more than twelve years or a fine of the fifth category, and

Article 294: A person who intentionally incites another to commit suicide, assists in the suicide of another, or procures for that other person the means to commit suicide, is liable to a term of imprisonment of not more than three years or a fine of the fourth category, where the suicide ensues.²

1 The research of which this article is a result, is funded by the Foundation for Law and Government (Reob), which is part of Netherlands Organisation for Scientific Research (NWO).

2 Rayar, L., and Wadsworth, S., *The American Series of Foreign Penal Codes. Vol. 30. The Dutch Penal Code*, Littleton, Fred B. Rothman & Co. (1997) 73, 200.

At the time the process of legal change began, a number of doctrinal approaches were in theory available to legitimate behaviour that at face value violates articles 293 and 294 of the Criminal Code. A first defence against a charge under articles 293 and 294 is that of ‘medical exception’, which argues that, unlike other offences against the person, the articles are implicitly not applicable to doctors. A second defence may be based on the doctrine of ‘absence of substantial violation of the law’: the idea that behaviour that violates the letter but not the purpose of the law does not constitute an offence. A third possible defence is offered by article 40 of the Criminal Code. This defence has two variants in Dutch law: the excuse of duress and the justification of necessity. The courts hold that the excuse of duress is not available to doctors in the case of euthanasia, since doctors are expected to be able to resist the pressures brought to bear by their patients. The justification of necessity applies to someone who, in a situation of conflict of duties, chooses to favour the value that from an objective standpoint is more important, even if this means doing something that in itself is forbidden. This defence was in the end the basis for the legalisation of euthanasia.³

In the 1960s and 1970s the term ‘euthanasia’ was used to describe a large and varied range of behaviour that led to the earlier death of the patient. These included refraining from treatment because of medical futility or because of the patient’s refusal, death as a side effect of pain relief, and actively ending a patient’s life (with or without his request). In 1977, a Dutch specialist in health law formulated a definition of euthanasia⁴ that in 1985 was largely adopted by the State Commission on Euthanasia. Since then in the Netherlands, euthanasia has officially been defined as ‘intentionally terminating another person’s life at that person’s request’.⁵ This definition coincides with the act specifically prohibited by article 293 of the Criminal Code. When a distinction is made, the term ‘euthanasia’ is reserved for killing on request as opposed to assisting suicide, but generally the two are treated together. I will follow this practice and use the term ‘euthanasia’ to cover both.

Before 1970 there was a general lack of interest in euthanasia and very little had been written on the issue in Dutch. This did not change much even when, in 1952, a doctor stood trial for killing his brother at the latter’s request.⁶ However, at the beginning of the 1970s this situation radically changed and

3 Griffiths, J., Bood, A., and Weyers, H., *Euthanasia and Law in the Netherlands*, Amsterdam, Amsterdam University Press (1998) 61-62.

4 Leenen, H.J.J., ‘Euthanasie in het gezondheidsrecht’, in *Euthanasie*, Muntendam, P. (ed.), Leiden, Stafleu (1977) 80.

5 Staatscommissie Euthanasie, *Rapport van de Staatscommissie Euthanasie. Vol. 1*, Den Haag, Staatsuitgeverij, (1985) 26. The State Commission notes that a broad consensus exists that the abandoning or stopping of medical treatment because it is seen as futile or refused by the patient and pain relief that leads to earlier death fall under ‘normal medical practice’ (*ibid*, 23-25).

6 *Nederlandse Jurisprudentie*, Zwolle, W.E.J. Tjeenk Willink, (1952) no. 275.

euthanasia became very much a topic for public debate. Several developments caused this change.

The 1960s represented a crucial watershed for Dutch society. From a conservative, tradition-bound country the Netherlands changed into a hotbed of social and cultural experimentation. The Netherlands took a prominent place in the sexual revolution, the legalisation of abortion, the democratisation of educational institutions, the questioning of religious authority, and so forth. Societal relationships also changed in this period, becoming more 'democratic', with a narrowing of the social distance between ordinary people and those in positions of authority. The Dutch came to expect to have their views listened to on issues that affected them. Similarly, the 1960s brought changes in views concerning the doctor-patient relationship, including a general acceptance of the idea of 'informed consent'.

Another circumstance usually associated with the growing interest in euthanasia is the development in medical technology. Such developments are assumed to have led to questions of a medical and ethical nature fundamentally different from any that had been asked before. In effect, doctors were given the ability to postpone death even when recovery was impossible. But prolonging life does not always go hand in hand with making it more bearable. Doubts concerning an unconditional 'duty to preserve life' became more and more persistent. If the answer to the duty question is 'no', and a doctor may decide not to engage in treatment that would prolong the patient's life, either because the patient did not want this or it was not in his interest to do so, then the question soon arises as to whether there is a major difference between acting and refraining from action.

In 1967, widespread public attention was attracted to the question of whether it ought to be permissible to end the life of a patient in a long and irreversible coma. A final stimulus to public debate was a book on medical ethics by a well-known Dutch doctor. His argument, formulated in an unusually provocative way, was that medical ethics must adjust to changes in medical technology, and that the motto of a new ethical code should be '[I]t is the doctor's duty to preserve, spare, and prolong human life whenever doing so makes sense'.⁷ He reasoned that a doctor may passively or actively shorten life that is no longer 'meaningful'.

3. The First Contributors: Courts, Pressure Groups and Legal Scholars

In the 1970s formulations of what came to be called the 'requirements of careful practice' for legal euthanasia can be found in three sources: court decisions, pressure groups and individual opinions, and reports of medical organisations.

7 Berg, J.H. van den, *Medische macht en medische ethiek*, Nijkerk, Callenbach (1969) 47.

3.1 District Court Leeuwarden

In 1973, a doctor stood trial for killing her mother at the latter's request. At the trial, the medical inspector testified that the average doctor in the Netherlands no longer considered it necessary to prolong a patient's life endlessly. In his opinion, pain relief that ran the risk of the patient dying sooner had, under certain conditions, become widely acceptable in medical circles. The conditions mentioned by the inspector were:

- that the patient is incurably ill;
- that the patient finds his suffering mentally or physically unbearable;
- that the patient has expressed the wish to die;
- that medically speaking the patient is in the terminal phase of illness; and
- that a doctor should be the one to accede to the request, preferably the doctor responsible for treatment.

The District Court largely agreed with the inspector's opinion. The only condition the Court did not accept was the requirement of the terminal phase. The Court convicted the defendant of having administered the morphine 'too quickly'.⁸ Despite the confusion between pain relief and euthanasia, the verdict of the District Court was the first authoritative formulation of the conditions for the legal shortening of life.

3.2 The contribution of pressure groups and opinion leaders

The conditions under which euthanasia is legal can be divided into substantive and procedural requirements. The substantive requirements refer to the request, the situation of the patient, and the doctor-patient relationship. Wide endorsement is to be found for the requirement that patients themselves must clearly express a wish to have life ended.

There was also general agreement that the patient's illness should be incurable. Substantial agreement also existed about the presence of suffering. The NVVE proposed that a necessary feature of suffering should be that it was 'unbearable and hopeless',⁹ and according to a working group of the Royal Dutch Medical Association, the suffering had to be impossible to relieve by any other means.¹⁰

Participants in the public debate disagreed over the situation the patient must be in. In the case above, the disagreement between the medical inspector and the Court concerned the importance of the 'terminal phase'. Lawyers supported the Court's view that 'terminal phase' should not be a prerequisite for

⁸ *Nederlandse Jurisprudentie* (1973) no. 183.

⁹ NVVE, *Rapport van de adviescommissie Wetgeving betreffende toelaatbare euthanasie uitgebracht aan de Nederlandse Vereniging voor Vrijwillige Euthanasie*, Amsterdam, NVVE (1978) 26.

¹⁰ KNMG Werkgroep Euthanasie, 'Discussienota van de Werkgroep Euthanasie', (1975) 30, *Medisch Contact*, 9.

the legal shortening of life.¹¹ An expert on medical ethics, Sporken, in contrast, deemed that euthanasia was only warranted in the terminal phase.¹²

The condition adopted by the District Court on the testimony of the medical inspector – that a doctor must be the one to accede to the request – was supported by nearly everyone. Whether the doctor had to be the doctor responsible for the patient's treatment became a subject for later discussion.

Although neither the inspector nor the District Court mentioned consultation as a requirement, the working group of the KNMG thought that a doctor considering euthanasia ought to discuss the matter with a colleague.¹³ A lawyer specialised in health law also thought this should be a prerequisite. He argued also for careful documentation.¹⁴

3.3 District Court Rotterdam

The next formulation of requirements by a court took place in 1981, when a woman, this time not a doctor, stood trial for having assisted the suicide of a friend. The District Court (Rotterdam) commented that suicide is not necessarily unacceptable in all situations and that the assistance of others can sometimes be indispensable. However, in the light of its prohibition in article 294 of the Criminal Code, such assistance could only be justifiable if certain requirements were met.

The verdict of the District Court emphasised that the request for help must be voluntary, well considered, lasting, and taken after being fully informed of the situation. Again 'terminal phase' was rejected as a necessary condition. Other conditions mentioned were: physical or mental suffering, prolonged and unbearable suffering, no alternative to improve the situation, and help had to be provided by a doctor. A new procedural requirement was added: care should be taken to avoid unnecessary suffering by relatives. The District Court held that the defendant had not met these requirements and found her guilty of assisting suicide.¹⁵

Following this verdict, the National Committee of Procurators-General, the highest authority in the prosecution system, decided that every case of death on request (article 293) or assisting suicide (article 294) that came to the attention of a prosecutor should be referred to the Committee for a decision on whether to prosecute. The object was to achieve national uniformity in prosecution policy. The conditions as formulated in the two cases described above were to

11 Till-d'Aulnis de Bourouill, H.A.H. van, *Medisch-juridische aspecten van het einde van het menselijk leven*, Deventer, Kluwer (1970) 103; Leenen H.J.J., 'Euthanasie in het gezondheidsrecht', above, 81-82.

12 Sporken, P., and Michels, J., *De laatste levensfase: stervensbegeleiding – euthanasie*, Baarn, Ambo (1975).

13 KNMG Werkgroep Euthanasie, Discussienota van de Werkgroep Euthanasie', above, 10.

14 Leenen, H.J.J., 'Euthanasie in het gezondheidsrecht', above, 144.

15 *Nederlandse Jurisprudentie* (1982), no. 63.

serve as guidelines for the decisions of the Committee.¹⁶ Although there had been cases before 1982 in which doctors had not been prosecuted after carrying out euthanasia, only after the decision of the Committee of Procurators-General can we speak of a prosecution policy with regard to euthanasia. In a later section I will return to the role the prosecution authorities played in the process of legal change.

4. The Contribution of the Medical Profession

We can learn what conditions doctors themselves thought important by both looking at the official position taken by the Medical Association in 1984 and at the behaviour of doctors themselves before that event as is reported by their writings¹⁷ and the information they gave in cases that came to court.¹⁸

In almost all cases the doctor claimed the patient made a clear request for euthanasia. The way the request was expressed differed, sometimes it was written, sometimes not. In all cases the patient indicated that the suffering was unbearable and that the doctor was able to recognise and agree that this was the case. Besides the level of suffering, doctors gave other reasons for their decisions, including their inability to relieve the suffering in any other way and their concern that the patient should die with dignity. Most doctors did not consider the terminal phase a prerequisite for carrying out euthanasia.

Few doctors consulted an independent colleague. Sometimes doctors discussed the case with other professionals such as pastors and nursing personnel. Members of the patient's family were nearly always involved in the decision-making. Sometimes relatives were not consulted, only informed, about the impending euthanasia, but often their approval was sought or they were asked to confirm the patient's request.

Doctors often filed certificates of natural death, thereby in effect concealing what they had done from the prosecution authorities. However, this did not necessarily mean that they had been secretive with others about the euthanasia. For example, two doctors later prosecuted for improperly filing certificates of natural death had talked about their intentions to other professionals involved with the patient such as a head nurse, and with the relatives.¹⁹

¹⁶ *Second Chamber of Parliament 1983-1984*, 18 100 Chapter VI, no. 3, 70.

¹⁷ Kenter, E.G.H., 'Euthanasie in een huisartspraktijk', (1983), 38, *Medisch Contact*, 1179-1182; Meyboom-De Jong, B., 'Klinische lessen: Euthanasie' (1983), 127, *Nederlands Tijdschrift voor Geneeskunde*, 946-551; Ponsioen, B.P., 'Hoe leert de huisarts leven met euthanasie', (1983), 127, *Nederlands Tijdschrift voor Geneeskunde*, 951-961; Unpublished document in file of Court of Appeals (Leeuwarden) in which 4 GP's gave information about 18 cases of euthanasia.

¹⁸ *Nederlandse Jurisprudentie* (1983), no. 407 and (1984), no. 43; (1984), no. 450 and (1985), no. 241; (1985), no. 709; (1987), no. 765; (1987) no. 287; Enthoven, L., *Het recht op leven en dood*, Deventer, Kluwer (1988) 94-183.

¹⁹ *Tijdschrift voor Gezondheidsrecht* (1985) 8, no. 44; *Nederlandse Jurisprudentie* (1988), no. 157.

A new stage in the development of the 'requirements of careful practice' was reached in August 1984, when the Executive Board of the Medical Association published a new policy on euthanasia.²⁰ The Board stressed that only doctors should be allowed to engage in actions that terminate life. Euthanasia was seen by the Board as an issue to be dealt with within the doctor-patient relationship.

The Board considered euthanasia performed by a doctor acceptable when the doctor had taken adequate steps to conform to the 'requirements of careful practice'. In the first place the request must be voluntary, well considered and lasting. In the second place the suffering of the patient must be 'unacceptable'. With this term the Board meant that the suffering must be lasting, unbearable and hopeless. Consulting a colleague was deemed indispensable, and the practice of filing a certificate of natural death was found unacceptable. In 1992, a full written documentation of the case was added to the list of requirements.²¹

The main difference between the actual behaviour of individual doctors and the position of the Board related to procedural conditions – the importance of consulting another doctor and not filing a false certificate. These were requirements doctors had often failed to comply with. The Board did not mention the importance of discussing the case with the patient's relatives, a requirement that doctors thought to be important.

Intermezzo: The Strategy of the Dutch Medical Association Explained

Let me digress somewhat at this moment to examine the role and strategy of the Royal Dutch Medical Organisation (KNMG). To date, the Association is the only national professional medical association that has taken an affirmative view on the legalisation of euthanasia. Others, such as the American Medical Association, have vigorously opposed legalisation of euthanasia or assisting suicide. Let me here mention some possible explanations for this departure by the Association.

By taking a leading position in the public debate the Association exhibited a well-recognised feature of the Dutch elite, who in the 1960s, according to James Kennedy,²² tended to interpret crises and problems as signs of inescapable social change. Attempting to forestall change did not seem to them a feasible policy. In Kennedy's view, the Dutch elite, after some hesitation, tended to support new ideas and be spokesmen for them.

In the debates on abortion in the 1960s, the Association had acted rather differently and by doing so had got themselves into difficulty. The social acceptance of abortion increased during that period and the idea that abortion, carried out by a doctor, fell within the bounds of an implicit 'medical exception' was widely shared. After 1969, a sort of legal vacuum had arisen in

20 KNMG, 'Standpunt inzake euthanasie', (1984), 39, *Medisch Contact*, 990-997.

21 KNMG, 'Richtlijnen KNMG en Nieuw Unie '91', (1992), 47, *Medisch Contact*, 30.

22 Kennedy, J.C., *Nieuw Babylon in aanbouw. Nederland in de jaren zestig*, Amsterdam, Boom, (1995).

which abortion, though still illegal, was in reality very much a fact. To satisfy the demand for abortion, special abortion clinics were set up.²³ This development meant that for practical purposes enforcement of the ban on abortion was no longer feasible.

Throughout the period of change in the 1960s, the Association had expressed opposition to abortion, and it was only in 1971, when the struggle was essentially over, that the Associations' position changed. Its Executive Board explained the change by reference to the social and political developments that in its view could not be stopped. Its new position was that 'the doctor's duty to give medical assistance can entail the decision to perform an abortion when he is asked to assist in an unwanted pregnancy'.²⁴

The new viewpoint of the Association led to vehement debate and a number of doctors took the position that the Executive Board of the Association could not speak for all doctors and that terminating a life violated a doctor's fundamental duty.²⁵ In 1972 some of these doctors founded the Dutch Association of Physicians, a 'pro-life' organisation.

In the 1980s a number of doctors feared that the Association would follow a similar course in the case of euthanasia. They did not like the idea of again being by-passed. In 1982 a working group was installed to formulate a policy on euthanasia. The working group took advantage of the recent abortion history to draw the lesson that it was better to join the public debate in its early phase. There was no longer any reason to fear a split in the organisation since adamantly pro-life doctors had already founded their own association.

The working group artfully avoided the ultimate ethical and legal polemics by stating that it was not its intention to address the question of the permissibility of euthanasia. Euthanasia was considered to be a fact of life and the only question was how medical practice was to be improved and regulated. The working group's formulation of policy was adopted by the association's Executive Board. During discussions at the general membership meeting on the new policy, the chairman stated that the Board did not want to take a standpoint for or against euthanasia. The purpose of the guidelines was to assist those doctors who were considering performing euthanasia. The debate closed with the assertion that the new policy was that of the Executive Board, and not necessarily that of all Dutch doctors.²⁶ In taking this strategy, the Association avoided openly offending opponents of euthanasia while at the same time it gave a clear signal to the outer world. It allowed the Advocate-General of the Supreme Court to argue in his farewell lecture in 1992, that the Association's

23 Outshoorn, J.V., *De politieke strijd rondom de abortuswetgeving in Nederland 1964-1984*, Amsterdam (1986) 119-175.

24 KNMG, 'Richtlijnen ten behoeve van de uitvoering van abortus provocatus', (1971), 26, *Medisch Contact*, 1025.

25 Haitsma Mulier-van Beusekom, C.A.H. (ed.), 'Het rondschriven over de richtlijnen inzake abortus provocatus', (1971), 26, *Medisch Contact*, 1197.

26 KNMG, 'Kort Verslag 186ste Algemene Vergadering II', (1985), 40, *Medisch Contact*, 438.

viewpoint had functioned as an *amicus curiae* brief for the decision that year in the first euthanasia case to reach Court.²⁷

5. The Contribution of the Supreme Court

The first time the Supreme Court ruled on a case of euthanasia was on 27 November 1984. The Court affirmed the holding of the Court of Appeals that the doctrine of ‘absence of substantial violation of the law’ was not an admissible defence. However, the Court concluded that the Court of Appeals had not properly considered the appeal to ‘conflict of duty’ (article 40).

‘[O]ne would have expected the Court of Appeals to have considered ... whether, according to responsible medical opinion, subject to the applicable norms of medical ethics, [that] this was, as claimed by the defendant, a situation of necessity’.²⁸

The Supreme Court considered specifically relevant the patient’s ‘unbearable suffering’ (including the prospect of increasing ‘loss of personal dignity’), the risk that it might become impossible for the patient to ‘die in a dignified manner’, and the existence of alternative ways to relieve her suffering. Not having consulted an independent doctor was not a sufficient reason for rejecting the defence of necessity, according to the Supreme Court.

In the second case to reach the Supreme Court, the idea of ‘medical exception’ was explicitly rejected. The Supreme Court held that the prohibition of euthanasia in article 293 did not appear to have been intended as subject to an exception for doctors. Furthermore, contrary to the defendant’s claim, there was no settled social consensus that euthanasia was a form of ‘normal medical practice’ that could be considered to fall within the ‘medical exception’ bracket. The Supreme Court did not, however, agree with the Court of Appeals’ rejection of the defence of necessity. The Court had not properly considered whether ‘according to responsible scientific opinion and according to norms applied in medical ethics, there had been a situation of necessity’.²⁹

In another case, the Supreme Court clarified the question of the death certificate. The Court upheld a decision that a doctor could not invoke the justification of necessity to a charge of filing a (false) certificate of natural death in a case of euthanasia.³⁰ Doing so, the Court of Appeals observed, undermines the system of legal control over the termination of life. The defendant’s reliance on

27 Remmelink, J., *Spanningen tussen recht en strafwet. Rede gehouden door Prof. Mr J. Remmelink ter gelegenheid van zijn afscheid als Procureur-Generaal bij de Hoge Raad der Nederlanden op de buitengewone zitting van het college op woensdag 29 april 1992*, 9.

28 *Nederlandse Jurisprudentie* (1985), no. 106, 459.

29 *Nederlandse Jurisprudentie* (1987), no. 607, 2124.

30 *Nederlandse Jurisprudentie* (1988), no. 811.

his oath of secrecy was rejected: this oath gives a doctor the right to remain silent, but not to give false information.³¹

5.1 The terminal phase again and the tightening of the requirement of consultation

Although from the very beginning, as we have seen, the courts had held that being in the terminal phase was not a necessary condition, the Minister of Justice in the early 1990s was adamant that it should be, and maintained that case law was not unambiguous on the point. In 1993, he ordered a number of doctors to be prosecuted on the grounds they had not met this requirement.³² In the next decision of the Supreme Court it became clear that the Court was not in agreement with the Minister.

The Supreme Court rejected the argument of the prosecution that the justification of necessity was not available in the case of assisting suicide given to a patient whose suffering is non-somatic and who is not in the terminal phase. It agreed with the holding of the Court of Appeals ‘that the wish to die of a person whose suffering is psychic can be based on an autonomous judgement’.³³ However, the Court concluded that in the circumstances of the case there was insufficient proof to support the defence of necessity, since there was no statement from an ‘independent medical expert who has seen and examined the patient himself’. Although, the Court observed, failure to consult a colleague does not in an ordinary case foreclose the defence of necessity, in the case of suffering that is not somatically based, evidence of consultation including actual examination of the patient, is essential because of the extreme care called for in such cases.³⁴

5.2 Evaluation of the Supreme Court’s contribution

The Supreme Court’s decisions brought much clarity to the issue. In the first place it clarified the grounds on which a defence could be based. The Supreme Court explicitly rejected the defences of ‘medical exception’ and ‘absence of substantial violation of the law’ but it held that a doctor can invoke the justification of necessity, choosing in a conflict of duties to do something in itself forbidden. The implications of this will be considered in a discussion of the ‘forbearance thesis’ in the next section.

Aside from the fact that the doctrinal basis for legally justified euthanasia had been settled, there was also clarification of the conditions with which doctors – the only ones who could legally perform euthanasia – must comply. The

31 *Nederlandse Jurisprudentie* (1987), no. 756.

32 Openbaar Ministerie, *Terug naar de toekomst. Jaarverslag Openbaar Ministerie 1993*, 's-Gravenhage, Ministerie van Justitie, (1994) bijlage 1.

33 *Nederlandse Jurisprudentie* (1994), no. 656, 3154-3155.

34 *Nederlandse Jurisprudentie* (1994), no. 656.

Supreme Court underlined the importance of the patient's request. The request must, in the terms of article 293, be 'express and earnest'. It must be explicitly made by the person concerned; it must be voluntary and well considered. The patient's suffering must be 'unbearable' and 'hopeless'. The suffering need not be physical nor is a somatic basis required. Non-physical suffering can include such things as the prospect of inhuman deterioration and the possibility of not being able to die in a 'dignified' way. Possibilities for treating the suffering must have been exhausted (or rejected by the patient).

In addition to these substantive conditions, the doctor who performs euthanasia must meet a number of procedural requirements. He must take adequate steps to satisfy himself with respect to the substantive requirements; he must consult at least one other doctor; the consultant should in principle be independent; if the patient's suffering is of non-somatic origin, the consultant must himself examine the patient and the doctor must not report euthanasia as a natural death'.

The substantive requirements for legally justified euthanasia are enforced through the criminal law. It was for some time unclear to what extent conformity with the procedural requirements was necessary for the successful defence of a criminal charge. It seems to be settled that deviation from these requirements does not necessarily stand in the way of an appeal to the justification of necessity. Thus, failure to comply with the oft-stated requirements, such as discussing the case with relatives and other personnel involved with the treatment of the patient, record keeping and carrying out the euthanasia in a professionally responsible way, were in most cases dealt with by means of medical disciplinary procedures.

Intermezzo: The forbearance Thesis Refuted

It is relevant here to deviate slightly to look at the question of whether, and for how many years, judicial policy in relation to euthanasia can properly be called one of 'forbearance'. Forbearance (*gedogen*) is an accepted legal practice in the Netherlands. It is one of several possible official reactions to a violation of the law and it consists of refraining, on policy grounds, from initiating a prosecution. In this sense, the policy formulated in 1982 by the Committee of Procurators-General can be seen as one of forbearance.

In 1984, as we have seen, developments in case law led to a situation in which a doctor who complies with the 'requirements of careful practice' can invoke the defence of necessity based on a conflict of duties. In effect, the verdict of the Supreme Court made euthanasia in conformity with the requirements legal.

In 1985, the Medical Association tried to get the Minister of Justice to clarify the policy of the prosecution authorities. They asked the Minister if the public prosecutors would base their prosecution decisions on the changed law.

When asked about this in the Second Chamber of Parliament, the Minister answered:

‘Broadly speaking, the public prosecutors will not prosecute a doctor, who in carrying out euthanasia complied with the requirements of careful practice developed in case law and formulated by the Medical Association’.³⁵

The opinion that a doctor who complies with the ‘requirements of careful practice’ may be assured of not being prosecuted for euthanasia was supported by a verdict of the Supreme Court in 1987. In this case a doctor who had carried out euthanasia requested the Court of Appeals to quash the indictment when criminal charges were brought. The Court did so. In the Court’s view the indisputable facts required the conclusion that prosecution of the doctor for euthanasia could not succeed, since if it went to trial it would soon become evident that the defendant had acted in a situation of necessity. The Supreme Court rejected the prosecution’s appeal on the ground that the arguments given by the Court of Appeals formed a sufficient basis for its conclusions.³⁶ The Supreme Court in this way definitively settled the matter: a doctor could indeed count on not being prosecuted as long as he had met the ‘requirements of careful practice’.

These two developments fundamentally changed the position of the public prosecutors. The Minister’s statement made prosecution unlikely, but the verdict of the Supreme Court gave prosecution no prospect of success. Since the prosecution authorities were no longer confronted with a violation of the law, decisions not to prosecute were henceforth based on legal rather than policy considerations, and it became impossible to describe the non-prosecution of doctors any longer as due to a policy of forbearance.

Although other authors are of a different opinion,³⁷ the conclusion to be drawn is that euthanasia policy in the Netherlands can only for a short period be referred to as a policy of forbearance. Since 1984/1985, euthanasia, when carried out by a doctor who has complied with the ‘requirements of careful practice’, has simply no longer been unlawful.

A second remark about Dutch forbearance policy is in order. Forbearance is often painted in negative terms. It is widely associated with turning a deaf ear or a blind eye to something, and thus doing nothing. Characterising the policy of the public prosecutors in the case of euthanasia in such a way does no justice to the facts. For example, in the first prosecution after the new prosecution policy in 1982, the local prosecutor was of the opinion that the doctor in question had complied with the ‘requirements of careful practice’. Nevertheless, the Committee of Procurators-General made the decision to prosecute.

³⁵ *Second Chamber of Parliament 1985-1986, Appendix*, no. 359.

³⁶ *Nederlandse Jurisprudentie* 1988, no. 157.

³⁷ See for example, Gordijn, B. and Janssens, R., ‘The prevention of euthanasia through palliative care: New developments in The Netherlands’, (2000), 22, *Patient Education and Counseling*, 36; G. van Oenen, ‘Gedegen gedogen. Over de waarde van gedoogbeleid voor de rechtstaat’, (2000), 20, *Filosofie en Praktijk*, 10-11.

The Committee doubted whether the doctor's assistant could be deemed an independent consultant and sought to clarify exactly what consultation entails. In other words, the policy of forbearance went hand in hand with active efforts to promote further development of the 'requirements of careful practice'.

The efforts of individual prosecutors to get doctors to report cases of euthanasia are another example of the active involvement of the prosecution authorities in policy development. The best known example is the efforts of the local prosecutor in the judicial district of Alkmaar. In the early 1980s, reporting a 'non-natural death' (euthanasia) was highly unattractive to doctors: it involved an investigation by the police with substantial emotional and practical consequences not only for the doctor but also for the relatives of the patient. The prosecutor in Alkmaar designed a procedure by which doctors could report euthanasia without having to undergo such unpleasantness. He promised the doctors in his district that they would not be troubled by the police if, in cases of euthanasia, they alerted the coroner and submitted a full written report. Evidence that the policy bore fruit is to be found in the rapidly increasing rate of reporting in the district of Alkmaar.³⁸

Another example of the active attitude of the prosecution authorities is the involvement of individual prosecutors in the formulation of protocols and guidelines for euthanasia by institutions such as hospitals and nursing homes. In the period 1989-1994 the number of Dutch hospitals and nursing homes to have an internal euthanasia policy rose considerably.³⁹ Most of these policies reflect the emerging legal norms and in many cases local prosecutors were actively involved in stimulating and assisting the institutions concerned.

6. The Contribution of Parliament

Until 1984, the role of political actors was very small in the process of legal change with regard to euthanasia. However, from 1980 onwards, political parties started to publish their points of view and in 1984 a first bill reached Parliament. The initiator of the bill thought that both the person who requested euthanasia and the doctor who agreed to carry it out were exposed to an unacceptable degree of legal insecurity. Regulation of euthanasia, in her view, was the responsibility of the legislature.⁴⁰ This bill was the first of a series of parliamentary efforts to deal with the problem of euthanasia.

In 1985, the earlier mentioned State Commission on Euthanasia brought out divided advice in which the majority pleaded for a change in the law. The Government – a coalition of Christian Democrats (CDA) and a right-of-centre

38 Josephus Jitta, A.N.A., 'Vervolgingsbeleid euthanasie' in *Juridische praktijkproblemen voor de arts*, Berkemeier, B.L., Sluyters, B., and Mulder Dzn., J.D., (eds), Leiden, Rijksuniversiteit (1987) 235-243; Enthoven, L., 'Het recht op leven en dood', above, 276-293.

39 Haverkate, M.A., and Wal, G. van der, 'Policies on Medical Decisions Concerning the End of Life in Dutch Health Care Institutions', (1996), 275, *Journal of the American Medical Association*, 435-439.

40 *Second Chamber of Parliament 1983-1984*, 18 331, no. 2 and 3.

liberal party (VVD) – in its reaction to the report, was inclined to the view that the time was not yet ripe for such a change. In case Parliament had a different view the government handed over a so-called ‘Discussion Draft of a Bill’.⁴¹ A year later this ‘Discussion Draft’ was dropped in favour of a proposal, left unchanged the Criminal Code, to standardise ‘the requirements of careful practice’ in the Law on Medical Practice. However, before Parliament could deal with the proposal, the Cabinet fell.

The following Government – a coalition of Christian Democrats and the Labour Party (PvdA) – proposed that before changing the law, there should be a national study of the practice of euthanasia. Such research could only take place with the co-operation of the medical profession. To ensure their co-operation one of the doctors long held wishes was met: a laid down procedure for euthanasia and guidelines for the police, so that matters relating to euthanasia should be handled as discretely as possible. In 1993 the majority of the Second Chamber rejected the first proposal⁴² – the one of 1984 – and gave legal status to the reporting procedure.⁴³ In 1994 a new Government had been formed in which, for the first time in modern Dutch political history, none of the confessional parties was represented. This Government initiated a replication of the first national research. The second study suggested that still less than half of all doctors reported euthanasia and to raise this figure it was decided to place a buffer between the doctors and the prosecution authorities. This was to take the form of Regional Assessment Committees that would investigate whether a case of euthanasia complied with the ‘requirements of careful practice’. If this was the case the Committees advised the prosecution authorities not to prosecute. In 1998, again some members of Parliament introduced a bill.⁴⁴ The second Cabinet without confessional parties that sat in government that year adopted this bill in somewhat revised form.⁴⁵

The fulfilment of the ‘requirements of careful practice’

As mentioned, there were two studies carried out into the extent and characteristics of euthanasia practice⁴⁶ which showed the degree to which doctors fulfilled the ‘requirements of careful practice’.

Essentially by 1990 all doctors were aware of the substantive conditions and procedural safeguards applicable to euthanasia.⁴⁷ As might be expected,

41 *Second Chamber of Parliament 1985-1986*, 19 359, no. 1 and 2.

42 *Second Chamber of Parliament 1992-1993*, 3404-3405.

43 *Second Chamber of Parliament 1991-1992*, 22 572, no. 1 and 2.

44 *Second Chamber of Parliament 1997-1998*, 26 000, no. 2.

45 *Second Chamber of Parliament 1998-1999*, 26 691, no. 1 and 2.

46 Maas, P.J. van der, Delden, J.J.M. van, and Pijnenborg, L., *Euthanasia and other Medical Decisions Concerning the End of Life*, Amsterdam, Elsevier (1992); Wal, G. van der, and Maas, P.J. van der, *Euthanasie en andere medische beslissingen rond het levenseinde*, Den Haag, SdU Uitgevers (1996).

47 Maas, P.J. van der, Delden, J.J.M. van, and Pijnenborg, L., *Euthanasia and other Medical Decisions Concerning the End of Life*, above, 197.

the substantive requirements that doctors themselves considered important were the most complied with. Euthanasia requires by definition an explicit request from the patient and doctors considered this request in almost all cases to come 'entirely from the patient himself'. The number of written requests increased from 35% in 1990 to 59% in 1995.⁴⁸ The extent to which life was shortened was a month or less in 90% of the cases. At the time the decision to carry out euthanasia was made, in almost 90% of cases the current treatment was only palliative and in the other 10% it was aimed at prolonging life, not at cure. In about 80% of the cases there were no longer any treatment alternatives, and in almost all the remaining cases the patient did not want further treatment.⁴⁹

From the 1995 research it became clear that the rate of reporting, while much improved from 18% in 1990, was still rather low (41%).⁵⁰ In 1995 in 92% of the cases of euthanasia the doctor said he had discussed the case with a colleague (84% in 1991) and in 79% the consultation was formal. The consulting doctor was seldom entirely independent.⁵¹

According to the findings, doctors discussed the situation with the family in 93% of all cases. It seems remarkable that a condition that has never attracted much attention from the Dutch Medical Association, the courts, or other enforcing agencies has nevertheless remained so prominent in medical practice. Discussion with nursing staff took place in about a third of all cases of euthanasia and virtually across the board the frequency of discussion with nursing staff declined between 1990 and 1995.⁵²

6.1 The Law on Termination of Life on Request and Assisting Suicide

In 2001, the legislature finally succeeded in enacting a euthanasia law. A doctor who, after carrying out euthanasia, notifies the coroner of this fact will have his actions judged by a Regional Assessment Committee. If the Assessment Committee determines that the doctor complied with the 'requirements of careful practice', the case ends there.⁵³

Doctors are not criminally liable if they fulfil two conditions. Firstly, they must adhere to the 'requirements of careful practice' as stipulated in the law and secondly, they must have reported the termination of life to the coroner. According to the 'requirements of careful practice' named in the law, the doctor must be convinced that the patient has made a voluntary, well considered

48 Griffiths, J., Bood, A., and Weyers, H., *Euthanasia and Law in the Netherlands*, above, 217.

49 Wal, G. van der, and Maas, P.J. van der, *Euthanasie en andere medische beslissingen rond het levenseinde*, above, 55.

50 *Ibid.*, 121.

51 *Ibid.*, 100-102. For further discussion on the developments in reporting as well as consultation see Klijn, A., *Will Doctors' Behaviour be More Accountable Under the New Dutch Regime?* in this Issue.

52 Griffiths, J., Bood, A., and Weyers, H., *Euthanasia and Law in the Netherlands*, above, 218-219.

53 *Second Chamber of Parliament 1998-1999*, 26 691, no. 2.

and lasting request; he must be convinced that the patient hopelessly and unbearably suffers; the doctor must have informed the patient about his situation and together with him be convinced that there is no reasonable alternative solution to the situation; the doctor must have consulted at least one other independent doctor and the ending of life must be carried out with due medical care.⁵⁴

The Law on Termination of Life on Request and Assisting Suicide adds essentially nothing to the 'requirements of careful practice' that emerged during the course of legal development. Formally speaking one might say that the demands for consultation and reporting received greater weighting. These have now been included in the law, while the courts did not see shortcomings in these two areas as a brake on 'excess' [*overmacht*]. However, during the parliamentary proceedings the Minister of Justice repeatedly stated that there would be no change in prosecution policy. The rather broader demands of doctors for discussion with the family and nursing personnel are not taken up in the new law.

Considering that the legislature believed that a change in the law would only sanction rather than undo matters already settled by the Supreme Court, one might ask why then enacting a change in the law took so long? One reason is to be found in the general features of 'social regulatory issues' such as abortion and euthanasia. Moral controversies tend to rage for a long time because of the intensity of ideological dispute. The Supreme Court's decision in such a case does not necessarily bring the matter to a close. Awaiting social developments – for example a consolidation of public opinion – is still an option for a legislature bent on minimising political risk.⁵⁵

This explanation is concomitant with the characteristic Dutch politics of conflict avoidance. Avoidance is traditionally accomplished by postponement of decision-making or by 'de-politicising' an issue as much as possible. Difficult political decisions are often sidestepped, at least for a time, by appointing advisory commissions. As in the case of euthanasia, a state commission was appointed in 1982 and all legislation was put on parliamentary hold until its report in 1985. Successive governments rarely pressure for quick results from such commissions. Postponement and de-politicisation can also be accomplished by initiating national research studies. Once again euthanasia is an example, the study of 1990 serving as an excuse for the further postponement of legislative action.

Perhaps most importantly, the Christian Democratic Party, opponents of euthanasia, figured in the different governments until 1994. It has been observed that the first verdict of the Supreme Court resulted in a political deadlock. A government bill to overrule the Supreme Court's decision would have been unacceptable to the coalition partners of the Christian Democrats – until 1989 the right-of-centre liberal party and between 1989 and 1994 the Labour

54 www.justitie.nl/a-beleid/fact/zelfdoding.

55 Tatalovich, R., and Daynes, B.W., 'Moral controversies and the policymaking process: Lowi's framework applied to the abortion issue', (1984), 3, *Policy Studies Review*, 219.

Party – but formally ratifying the verdict in legislation was equally unacceptable to the Christian Democrats.⁵⁶

But even both Governments after 1994, in which the confessional parties had no representation did not put much energy into securing legislation. The guiding principle seemed to be not offending the Christian Democrats (and those members of their own parties who had reservations) and to continue the search for common ground. The government's hand was ultimately forced by a private member's bill that quickly attracted a parliamentary majority. At that point the Government decided to take things into its own hands and introduced the bill that finally became law.

⁵⁶ Hees, M. van, and Steunenberg, B., 'The choices judges make. Court rulings, personal values, and legal constraints', (2000), 12, *Journal of Theoretical Politics*, 305-324.

Euthanasia: the Process of Legal Change in Belgium

Reflections on the parliamentary debate

Maurice Adams

1. Introduction

To date, euthanasia is a punishable offence in Belgium. It is not, however, as in the Netherlands, treated as a discrete offence. Belgian criminal law does not recognise the concept of euthanasia and as a consequence applies some general principles from the Penal Code of 1867: article 393 relating to voluntary manslaughter, and article 394 covering murder.¹ These offences are all dealt with by the so-called Assize Court.²

The matter is more complicated when it comes to assisted suicide. Suicide is not considered a criminal offence in Belgian law, and therefore neither is assisting in suicide. According to a number of authors, however, the law can be interpreted in such a way that assisted suicide can be indirectly punishable. They refer here to article 422*bis* of the Penal Code that deals with the offence of omission, i.e. not giving help to someone in extreme danger.³ The lack of any Belgian case law on this issue, however, means that it is unclear whether such an argument is valid.

Finally, it is generally accepted in Belgium that a doctor is not obliged to continue medical treatment that has no longer any curative or therapeutic effect on a (mortal) disease, and that a possible shortening of life through administering pain relief is an acceptable side effect.⁴

The legislature in Belgium has delegated authority for laying down rules of conduct to a number of professional organisations. Non-compliance to these rules can result in temporary or even permanent professional suspension. In this context the Belgian Medical Association ('Orde van Geneesheren') was

1 Perhaps article 397 of the Penal Code relating to poisoning could be applied. Poisoning is seen as homicide by means of substances that can more or less result in quick death. Concerning the legal context in which euthanasia is situated in Belgium, see Velaers, J., 'Het leven, de dood en de grondrechten. Juridische beschouwingen over zelfdoding en euthanasie', in: *Over zichzelf beschikken? Juridische en ethische bijdragen over het leven, het lichaam en de dood*, Antwerpen, Maklu (1996), 470-574 and Groot, E. de, *Leven tot in de dood. Omtrent euthanasie*, Brussel, VUBPress (1997), 25-77.

2 The Belgian criminal court that handles serious offences and works with a jury.

3 See on this Vuye, H., 'Schuldig hulpverzuim. Een analyse van artikel 422*bis* Sw, in het licht van de algemene leer van de omissie in het strafrecht', in *Liber Amicorum Jean du Jardin*, Antwerpen, Kluwer (2001), 431-480.

4 See for a more comprehensive account, Strubbe, E. and Nys, N., 'Medisch handelen en nalaten rond het levenseinde bij een wilsbekwame patiënt' (2000) 21 *Panopticon*, 423-440.

asked to establish Rules of Conduct for the medical profession.⁵ In Heading II of Chapter IX of these rules (regarding the approaching end of life), article 95 reads: “The physician may not intentionally cause the death of one of his or her patients or help them to take their own lives.” Article 96 of these same rules states that: “When the death of a patient is approaching and he is still in some state of awareness, the physician is bound to give moral support and to give what help necessary to reduce physical and psychological suffering in order to allow the patient to die a dignified death. When the patient has entered a state of unconsciousness the physician must limit himself to giving palliative care”. Additionally, according to article 97, the physician must consult at least one colleague and the patient him or herself when starting or stopping a course of treatment, and if needed ask the opinion of the patient’s close family or legal representatives. Finally, article 98 informs us that if, on the basis of scientific evidence, the patient is brain dead, then he or she must be declared legally dead.

It is striking that the Penal Code, unlike the Medical Rules of Conduct (in article 95) gives no ruling on assisted suicide. Above all, in law doctors are obliged to give some sort of palliative care. Article 97 of the Rules of Conduct makes clear reference to stopping curative care and the unnecessary prolongation of treatment. If the patient is conscious its *opinion* will be asked (it does not say *agreement* or *decision*), if otherwise, its next of kin or representatives will be consulted. The Medical Rules of Conduct indicate therefore that the doctor may not perform euthanasia but can administer pain relief that may shorten life. The Rules of Conduct appear, then, on balance to give room for a more subtle approach to the question of dying than the Penal Code.

It is worth noting that until 2000 no legal case on euthanasia had ever been brought to court, despite the fact that doctors often admit that they act in a manner likely to cause death. We do not know therefore whether the notion of a ‘justification of necessity’⁶ as accepted by the Dutch Supreme Court in the context of euthanasia is likewise applicable in Belgium. For the Belgian doctors this has led to legal uncertainty.⁷

One reason why there have been no legal cases until recently is that Public Prosecutors never pursued any. Since very recently, however, a few cases are prosecuted indeed. This is perhaps due to the impetus of public discussions on

5 On these Rules of Conduct, see Groot, E. de, ‘Leven tot in de dood. Omtrent euthanasie’, above, 51-62.

6 The legal concept of justification of necessity applies to someone who in a situation of conflict of duties chooses to favour the value that from an objective point of view is more important, even if this means something that in itself is forbidden. See on this Weyers in this Issue.

7 There was in fact a case brought at the beginning of 1960s in the context of a so-called soft-non baby: a woman who gave her recently born and badly deformed baby a lethal mixture which she received from her doctor after putting much pressure on him. But the jury in the case at the Assize Court in the city of Liege acquitted both the woman and her doctor on 10th November 1962. In essence, however, this was not a case of euthanasia since there was obviously no request from the baby. See Viernet, J., Riquet, M. and Roumagnon, Y., ‘Réflexion sur le proces de Liege (le point de vue religieux, moral et médical)’ (1963) *Rev.Sc.Crim.*, 83-100.

the issue. For example, in January 2000, on receiving complaints from nursing staff in the city of Liege, two doctors (a cardiologist and an anaesthetist) were arrested on suspicion of administering a lethal dose of barbiturates to a man with a longstanding and chronic lung problem. This was at the man's request and in consultation with his family.

2. The Process of Change

In order to be able to understand the process of legal change, it is important to state that Belgium, as a federal state, has a particularly complex structure. It consists first of all of three language groups, of which the Dutch and French languages dominate (there also exists a small and constitutionally recognised German speaking group in the east of the country). These dominant language groups virtually coincide with Flanders (Dutch-speaking) and Walloon (French-speaking) areas. The capital of Belgium, Brussels, is officially bilingual, but in fact it is to an important degree a French-speaking city. This factual and official multilingual character of Belgium means that all activities, including the format of official, non-official and political bodies and committees, are either organised as such that at least Dutch- and French-speaking Belgians are equally represented, or even separately organised in at least Dutch and in French. Moreover, Belgium is also an extreme example of a society which is not just linguistically but also ideologically divided. In politics this means, among other things, that in ethical questions Catholic groups and political parties usually stand opposed to non-confessional parties. This structure of Belgian society led the political scientist Lijphart to call Belgium "the most thorough example of consociational democracy".⁸ In such a democracy political power rests with a pragmatic political elite, that will always try to solve societal and political problems in such a way that all parties concerned can recognise themselves in the final solution. This in order to keep the political system stable, and to prevent political parties to estrange from the political system. This system functions of course especially among the governing parties. However, in the context of the political discussion on euthanasia, one of the key players in Belgian politics, the Christian Democrats, are since July 1999 for the first time in 40 years no longer represented in government. This has provoked a completely new political dynamics.

2.1 The first phase: 1980-1997

The founding in 1980 of two associations – the Flemish 'Right to Die with Dignity' ('Recht op Waardig Sterven') and the Walloon 'Association pour le

⁸ Lijphart, A. (ed.), *Conflict and coexistence in Belgium*, Berkeley, Berkeley University Press (1981), 1. See also Lijphart, A., *Democracy in Plural Societies*, New Haven, Yale University Press (1977), 1.

Droit de Mourir dans le Dignité – could perhaps be seen as a start – though still in a limited way – of organised action to recognise the right to euthanasia. Their influence, certainly at that time, was rather small because the subject had not yet become a real public or political issue and both associations were politically radical in ideology – in this case strictly and strongly liberal. Socially, there appeared no support for their ideas and in addition at the time, in a denominationally segregated Belgium, the liberals were in a very specific niche in the political landscape. Politically the liberals were also in a minority and therefore co-operation was problematic. They thus stood little chance of having any political influence. This was exacerbated by the fact that traditionally, even in liberal circles, there was no unqualified support for an intrinsic right to euthanasia, as will be seen later in this article. The most important political faction in the government from the 1950s, the Christian Democrats (in practice representing Roman Catholic belief) was strongly against any legislative provision for euthanasia. As will become evident, until the 1990s, it had been the Christian Democrats who, as a matter of principle, had rejected or blocked the regulation of euthanasia.

The first study commissions

This political stonewalling did not, however, mean there were no developments at societal level. From the 1970s euthanasia was regularly in the news and in addition was also the subject of, albeit very occasional, political debate.⁹

However, from the middle of the 1980s, the Christian Democratic parties shifted their strict position on the issue and euthanasia and end-of-life decisions became at least debatable. This was stimulated by technological developments in medicine and biology and led to the setting up of a Commission in 1983 by Walloon and Flemish Christian Democrats to study the ethical issues involved.¹⁰ The premise for their work, according to the Commission's report of 1985, was that the pluralism of society, its democratisation, the autonomy of morals as opposed to religion, and the development of technology are all factors that bring about radical social change. Traditional values are therefore also subject to chance. The commission looked at a number of issues, mainly of a medical nature, such as the inclination to continue treatment even where there are no benefits, the removal and transplantation of organs and tissues, and the carrying out of medical research. Research regarding useless medical treatments led to making a distinction between active and passive euthanasia. According to the Commission the former should be ruled out, whereas the latter

9 For example, in 1971, the Belgian state broadcasting network organised a TV debate on the subject.

10 See Delfosse, M.L., 'Ethische problemen', in: *Tussen Staat en Maatschappij 1945-1995. Christen-democratie in België*, Dewachter, W. (ed.), Tiel, Lannoo (1995), 498-518.

was permissible as long as it was accompanied by palliative care and intensive counselling.¹¹

Meanwhile, in 1986, the Flemish Christian Democratic Deputy Minister for Health and the Handicapped organised a national colloquium entitled 'Bio-ethics in the 1990s'. Prior to the colloquium, which took place in 1987, there were a number of preparatory meetings held by multidisciplinary and ideologically pluralistic working groups. The subgroup considering 'Ending Life', recommended altering the Penal Code on behalf of doctors who carried out euthanasia.¹² The proposal was not taken up because, among other things, the Liberal (!) Minister of Justice was opposed to it. Nevertheless, the colloquium provided a stimulus for the formation of a pluralistic national advisory committee on bio-ethics, since the Deputy Minister mentioned before announced the setting up of such a body during the closing session of the colloquium.¹³ This committee got the final go-ahead in 1993, and was able to commence its work in 1996. I will return to this development in the next section.

The first bills

In the 1980s, for the first time, proposals for a bill were regularly put forward from virtually the whole political spectrum, with the exception of the Christian Democrats. None of these proposals reached the final stages.¹⁴ Moreover, they were all proposed by individual Members of Parliament, which meant that they were not necessarily official party initiatives, or had party support.

There was a proposal for a bill in 1984 by French language liberal circles against therapeutic pointless medical treatment for the terminally ill (a proposal put forward again in 1986). This proposal seemed superfluous since it was already generally accepted in Belgium that doctors could stop pointless treatment. The proposal was therefore mainly geared to providing doctors with more clarity regarding their medical behaviour. In 1985, a Walloon Member of Parliament from the socialist camp proposed a bill that laid down rules regarding the doctor/terminally-ill patient relationship. It covered the legalisation of, among other things, euthanasia and assisted suicide for competent and incompetent patients, and also made provision for ending the lives of patients considered clinically dead.¹⁵

11 In 1990 the activities were taken over by another work group which in a report of 199 gave a number of recommendations on the various medical procedures regarding ending life. The proposals, however, were mainly the same as in the report of 1985.

12 All documents of this colloquium are to be found in Demeester-De Meyer, W. (ed.), *Bio-ethica in de jaren '90*, Gent, Omega (1997), 514 +143 p.

13 The idea for such an advisory body had already been put forward in 1984 in the Senate, and in 1986 through in the Chamber of Representatives. In both cases the impetus came mainly from Christian Democrat representatives.

14 For an overview of the bills see Coolsaet, A., 'Een overzicht van de Belgische wetsvoorstellen inzake euthanasie' (1995-1996) 1 *Tijdschrift voor Gezondheidsrecht/Revue de droit de la Santé*, 262-271.

15 An amended version of this proposal for a bill was again presented in 1986 and in 1988 in a somewhat revised version.

It is also worth mentioning a proposal for a parliamentary motion in 1988, by a French-speaking Christian Democrat, asking the federal government to thoroughly research the practice of euthanasia in Belgium, keep the population informed on the ongoing state of affairs, and come up with concrete proposals to make sure that human life was absolutely respected. The proposal was rejected.

In 1993, a member of an eccentric Flemish party submitted a proposal for a bill that reserved euthanasia for patients in the last phase of a terminal illness or for those suffering from a disease leading to death. In the same year a proposal for a bill was also submitted by the Flemish Greens. Ethically this proposal was the most liberal ever introduced in Belgium, proposing 'medical hopelessness' as the sole medical criterion demanded before euthanasia could be considered.

In 1994, a French-speaking member of the liberal camp introduced a proposal for a bill. It addressed only the problem of euthanasia *sensu stricto*, thus from the beginning rejecting any form of treatment that ended life without a valid request from the patient. 'Living wills' were according to this Member of Parliament also no solution to the issue, since 'they are only based on abstract considerations and cannot be considered an expression of a concrete desire arising from an actual situation'. Other themes such as palliative care also received insufficient attention in this proposal.

Finally, I would like to mention a proposal for a bill submitted by the Dutch-speaking liberal camp after extensive discussion within the Flemish liberal movement. The proposal recommended regulating palliative care, and restricted itself exclusively to terminally ill patients, but also regulated so-called living wills. And in 1996, a joint proposal for a bill by the Flemish and Walloon socialist parties stated that euthanasia should be considered only where there was a clear case of an incurable condition (caused either by illness or accident) which a medical doctor was unable to control sufficiently. The proposal also stipulated that there should be persistent and unbearable suffering or distress (either where the patient could give consent or where the patient could not give consent but had previously made a living will).

None of the proposals for a bill mentioned stood a chance of acceptance at the time they were proposed. The latter three bills were reintroduced a couple of years later in 1999, virtually unaltered, when the Christian Democrats were no longer in government.

2.2 1997-1999

Advice of 12 May 1997

One of the most significant events relating to euthanasia is undoubtedly the 12 May 1997 Advice of the Advisory Committee for Bio-ethics.¹⁶ The Committee was set up in 1993 after years of political wrangling, but only got up and running in 1996.¹⁷

It was remarkable that the Committee could give its advice on euthanasia in 1997 already, since this was one of the most sensitive and complex issues it was ordered to deal with in 1996. The Advice was important because it led to a certain depolarisation and neutralisation of the differences of opinion. It made it possible to have a debate on euthanasia in a calmer and more rational manner. Until then, the debate had been almost wholly dominated by ideological stances and antagonistic non-communication. The Committee was set up, according to article 1 of the Committee's Founding Statute, to inform and advise government and the public on problems arising from research and its implementation in the area of biology and health care, and to explore the ethical, social and legal aspects of the issues involved, and in particular the rights of the individual. It consists of 35 members – doctors, lawyers, ethicists, psychologists and sociologists – and is ideologically and linguistically balanced. In the Belgian context this means an equal number of Catholics on the one hand and atheist and agnostic people on the other hand, as well as a balance in the numbers of Dutch and French speaking members. From its inception the committee has been organised into subcommittees consisting of twelve members that again must reflect a balanced composition. The full Committee decides upon the findings and proposals of the sub-committees and where necessary these are then amended and approved. The Committee can put forward recommendations on its own initiative, or at the request of leaders of parliament, members of the government, or chairpersons of hospital ethical committees etc.

The proposals and points of view of members of the Committee do not have to be based on a 'majority' point of view. Significantly no vote is taken on the different opinions existing within the Committee. In this sense the Committee is mainly an informative body with the consequence that recommendations include *all* the different and sometimes strongly divergent points

16 See the Belgian Advisory Committee for Bio-ethics, Recommendation No 1, 12 May 1997, on the desirability of legislation on euthanasia. Consult: www.health.fgov.be/bioeth/ On the recommendation itself, see Vermeersch, E., 'Euthanasie in België' (2000) 21 *Filosofie en Praktijk*, 48-56 en Jans, J., 'Euthanasiegesetzgebung in Belgien. Eine Übersicht über die politisch-ethische Debatte 1997-1999', in: *Ethik und Gesetzgebung. Probleme – Lösungsversuche – Konzepte*, Bondolfi, A. en Grotenfeld, S. (eds.), Stuttgart, Verlag W.Kolhammer (2000), 175-187.

17 In general on the working of this Committee see Van Neste, F. van, 'Pluralisme en tolerantie in het Belgisch Raadgevend Comité voor Bio-ethiek' (1999) 66 *Streven*, 891-897.

of view. All the proposals are given equal weight regardless of whether they reflect the view of one or all members. In fact the Committee is obliged to do so.

The Committee's advice of 12 May 1997 covers the desirability of legislation on euthanasia, where euthanasia – clearly influenced by the Dutch discussions – is taken to mean the 'intentional ending of life by someone else than the person concerned, at the request of the latter'. In fact the Advice falls apart in four different proposals, such that each member of the Committee can find its position back in the full advice.

Proposal 1 related to a change in the Penal Code to legalise euthanasia, with a procedure to control *a posteriori*. In the Netherlands this is the accepted ruling since April 2001.

Proposal 2 also related to a procedure to control euthanasia *a posteriori*. The difference with the first Proposal being that the existing restrictions in the Penal Code were observed but there were conditions introduced that made it possible for the doctor to make an appeal on the so-called 'state of necessity'.¹⁸ This model was obviously inspired by the Dutch ruling between 1993 and 2001.

Proposal 3 comprised a procedure to control *a priori* the most important medical decisions taken at the end of life (thus not only euthanasia). This Proposal also upheld restrictions in the Penal Code, and set out legal conditions covering the grounds on which a doctor could declare a 'state of necessity'.

Proposal 4 upheld the position that euthanasia should under no conditions be allowed and was therefore illegal.

The Committee also stressed the need to organise a parliamentary debate on these questions and expressed its concern over what in the Advice was called 'uncontrolled euthanasia': i.e. doctors ending a patient's life without consulting them or their family, often putting pressure on nursing staff into going along with them. This last concern expressed by the Committee was not supported by any reliable statistical data.

The views of the different members of the Committee were, in fact, not so divergent as was first assumed. According to one of the members there was a noticeable degree of unity around Proposal 3 (although no unanimity or consensus).¹⁹ This unity of approach was mainly due to the fact that leading Catholics from both sides of the language divide in Belgium were prepared under strict conditions to accept euthanasia. The Advice itself and how it was arrived at made it possible to have a mature discussion of the issue. It marked in this respect a noticeable difference from the way an advice on abortion was produced by an *ad hoc* Committee in the 1980s. That simply consisted of a polarised discussion of those for and those against abortion.

18 See Weyers, H., 'Euthanasia: the Process of Legal Change in the Netherlands', in this Issue, and footnote 6 above.

19 Schotsmans, P., 'Wenselijkheid van een wettelijke regeling van euthanasie. Het eerste advies van het Belgisch Raadgevend Comité voor Bio-ethiek' (1997) 7 *Ethische Perspectieven*, 87. However, some members of the committee did not agree with this point of view.

In fact, indirectly, it was the painful history behind the passing of the Belgian abortion law that led to an impulse for finally setting up the Advisory Committee in 1993. It should be remembered that the abortion law was passed with a Liberal-Socialist majority and thus without the co-operation of the Christian Democrats who were then nevertheless still part of government. As a reaction to this the Christian Democrats signed up in government agreements an explicit ban on these kind of fluctuating majorities on ethical matters, making it impossible to pass laws without the consent of the Christian Democrats.

The Advice of the Committee on euthanasia formed the basis for a debate between Members of Parliament and experts, including those of the Advisory Committee, in the Belgian Senate on 9th and 10th December 1997.²⁰ It was no coincidence that the debate was in the Senate, since after constitutional reforms in 1994, the Senate became the primary vehicle for, among other things, ethical debates. There was now in fact consensus in the Senate to legislate on euthanasia, as became apparent in the statements of the most important political parties the week before the debate. The Flemish and Walloon Christian Democrats felt themselves most in tune with Proposal 3 of the Committee and stated that explicit attention be given to the development of palliative care to prevent the demand for euthanasia. The two socialist parties were more in favour of Proposal 2. The Flemish Liberals also opted for Proposal 2, while the Walloon Liberals had no clear standpoint, except that they believed the existing law offered enough room to provide for any situation that might arise at the end of life. The Flemish Greens defended the right of life but could also support Proposal 3. Finally, the Democratic Flemish Nationalists wanted more attention to be given to the development of palliative care with secondary consideration for the regulation of euthanasia. The large majority of political parties wanted anyway to avoid the kind of polarised debate that had taken place on abortion in the 1970s and 1980s. At the end of the day, only the extreme right Flemish Block was against any form of regulation of euthanasia and thought the debate on it pointless and dangerous.

During the first day of the actual debate in the Senate the emphasis was on the Advice of 12 May 1997, including the opinions of experts. The second day focused on a debate between the senators themselves. That again gave rise, as in the Advisory Committee on Bio-ethics, to a consensus around Proposal 3. This led to a political agreement that the Senate Commission for Justice (dealing with criminal issues) and the Commission on Social Affairs (dealing with health care issues) should together frame a bill. The Advisory Committee on Bio-ethics was additionally asked to formulate an Advice on non-competent patients and on so-called living wills, themes that the Advisory Committee had not addressed in their Advice of 12th May 1997, despite having been asked to do so. From the many opinions for and against legislation that appeared in the

20 A complete report of this debate can be found in *Handelingen van de Belgische Senaat* 1997-98 and 10 December 1997, 3891-3954.

daily newspapers in the following months, one may deduce that the political will to legislate acted as a catalyst for public debate.

The next political step was that in March 1998, the Flemish Socialists declared that legislation that dealt only with euthanasia was too limited. They also wanted legislation to cover comatose patients, handicapped new-borns and those suffering from serious dementia. Because at the time the agreement reached to prepare a bill depended on a delicate political balance, this declaration appeared somewhat premature and shocked the Christian Democrats. This, together with concern for other political matters, led to developments coming to a virtual standstill. However, the decline in political interest in the matter from 1998 did not mean no developments occurred. For example, a multidisciplinary pilot study appeared in 1998 on the actual use of euthanasia by doctors. The study looked at the situation in only one Flemish city,²¹ but it was, nevertheless, the first scientific study of end-of-life medical treatment.²²

Advice of 22 February 1999

On 22 February 1999, the Advisory Committee on Bio-ethics came with an advice relating to ending incompetent patient's life.²³ The Committee had not referred to this in the first Advice on euthanasia, despite a specific request to do so from the parliamentary chairman. In contrast to the Advice on euthanasia, in this Advice all the classic ideological and ethical divisions and differences of opinion on the issue came out. As far as the Advice regarding euthanasia is concerned, there had been a will to work together, but in this Advice there was no longer any question of that. There were three directly opposing positions on the Advice. The first group rejected any form of euthanasia and thus any form of ending life without conscious consent. The second wished to recognise end-of-life treatment without conscious consent on condition that there was a living will and consent from an impartial representative. Finally, a third group thought end-of-life treatment should under certain conditions also be possible in case there was no existing consent. This Advice, precisely because of the divisions it provoked, played no further role in the political debate at least up till the middle of 1999 and got far less attention when compared to the first one.

In the run up to the elections of June 1999, the Socialists emphasised once again that a following government should legislate on euthanasia in accord with Proposal 2 of the Advice of 12 May 1997, including a ruling for the incompetent. The Christian Democrats reacted by saying that only a ruling in accord with Proposition 3 of the May 1997 advice would be acceptable to them

21 Mortier, F. et.al., 'End-of-life decisions in medical practice in the city of Hasselt (Flanders, Belgium)' (2000) 14 *Bioethics*, 254-267.

22 According to a study published in 1999, six out of ten doctors had at some time carried out euthanasia in Belgian intensive care-units. Vincent, J.L., 'Forgoing life support in Western European intensive care units: the results of an ethical questionnaire' (1999) 27 *Critical Care Medicine*, 1626-1633.

23 Belgian Advisory Committee for Bio-ethics, advice nr 9 dated 22 February 1999 regarding ending life without the conscious consent of the patient.

and that they had great reservations in accepting any ending of life without conscious consent. They added again that a government with Christian Democrats would only be possible if legislation on issues of an ethical kind could not be approved by a fluctuating majority.

2.3 1999-2001

Autumn 1999: the government bill

National elections took place in Belgium on 13th June 1999. Unexpectedly, for the first time in forty years, it became possible to form a government without the Christian Democrats. And so happened. The new federal government was a coalition of Liberals, Socialists and Greens, which was quickly dubbed the 'purple-green' or 'rainbow' coalition. In Section 11 of the government accord (July 1999), under the heading 'Ethical Questions', it states that: 'In recent years biological and bio-medical science has made significant advances. Fundamental interference has become possible in human life. However, our country has not yet succeeded in working out a legislative framework appropriate to this development, and that would fit a modern and democratic society. Parliament has to be able to fulfil its responsibility on such matters, *including euthanasia* (emphasis added), and must do this on the basis of each individual's convictions.'

This call on the federal parliament to legislate on euthanasia did not fall on deaf ears, because after new Senate hearings with several members of the Advisory Committee for Bio-ethics, in October 1999, legislation was initiated. Four parliamentary factions of the governing coalition reanimated a number of old proposals for a bill, and in the media stressed their willingness to come to a definitive undertaking in the not too distant future; this would be done in consultation with the opposition. The Flemish and Walloon Christian Democrats also each proposed a bill, and thus within a very short period of time there were six proposals on the parliamentary table.²⁴

There was a common premise underlying all the proposals for a bill except those of the Christian Democrats: the right of the individual to autonomously make end-of-life decisions. Each proposal was also geared towards legalisation: the Penal Code was changed so that euthanasia (under particular conditions) would no longer fall under the terms of manslaughter or murder. Otherwise the proposals were very heterogeneous. This was most clearly apparent in the medical conditions laid down.

In the Flemish Greens' proposal for example, simple medical hopelessness was sufficient ground for euthanasia to be carried out. In the explanatory

24 An overview and discussion of these proposals can be found in: Adams, M. and Geudens, G., 'De regulering van euthanasie in België. Principiële beschouwingen naar aanleiding van een aantal recente wetsvoorstellen' (1999-2000) 63 *Rechtskundig Weekblad*, 793-817. Also Adams, M. en Geudens, G., 'Euthanasie als politiek-ideologische splijtzwam? Variaties op de thema's autonomie en zelfbeschikking' (2000) 67 *Streven*, 401-413.

memorandum this was broadly defined to the extent that patients with advanced Multiple Sclerosis for example, would be able to ask for euthanasia legitimately.

The proposal of Socialist factions, both Flemish and Walloon, stated that there had to be a disease, caused either by accident or illness, which was incurable and untreatable. However, their proposal also required the presence of persistent and unbearable suffering or distress (for conscious consent) or irreversible coma (if no consent could be obtained, providing there was a living will). In this respect their proposal was stricter than that of the Greens.

The respective proposals of the Liberal factions were the most stringent of the governing parties because euthanasia was explicitly reserved for the last stages of life. Thus the Walloon Liberals talked of the 'approaching and inevitable death' and the Flemish Liberals of the 'terminal phase'.

The respective Christian Democrat proposals both implicitly but firmly supported the concept of mercy, and thus placed strong emphasis on euthanasia as the last remedy, only to be considered for those who were terminally ill and beyond palliative care. They utterly rejected a ruling on incompetent patients.

As far as the proposals of the governing parties are concerned, there were thus some differences of approach between them. Three of them concerned in one or another form living wills. The Walloon Liberals categorically rejected this instrument. Clear differences were also present with regard to palliative care. Whereas in most proposals this aspect was given little attention, the Flemish Liberals explicitly coupled euthanasia with the extension of a full palliative care package.

The Christian Democrats were *de facto* quickly excluded from all discussions. On 20th December 1999, a mere six weeks (!) after the issue of euthanasia had been placed on the parliamentary agenda, the coalition parties unexpectedly came up with a bill that formed a compromise between the four proposals that these same government parties had only recently introduced. This despite the fact that the different proposals had only just been put to the relevant Senate Committee, but were not even discussed. The stated aim of this new proposal was 'to embrace the four proposals of the governing parties that had been introduced at the beginning of the Senate hearings'. This would make it easier to have 'an open and comprehensive debate'. In fact the compromise bill was virtually the same as that proposed by the Socialists. The majority proposal on euthanasia was also linked to a proposal for a bill concerning palliative care and a bill proposing an evaluation commission regarding the application of euthanasia.

These events meant a strong break from the careful political consensus that had been built as a result of the debate in the Senate in 1997. This was not wholly unexpected in the light of what had gone before, because it had been clear since 1998 that both socialist parties were no longer willing to identify with the consensus.

The most important differences in understanding between the government parties and the Christian Democratic opposition over the content related, and at the moment still relate, to five aspects.

- The government parties considered that when a patient suffered from a) persistent and unbearable pain or distress which could not be relieved, which b) is the consequence of a severe and incurable illness, this, in principle, sufficiently satisfied the condition to move to euthanasia. On the basis of the majority bill, whether unbearable and persistent pain or distress is present or not, is largely for the patients themselves to decide. The French- as well as the Dutch-language Christian Democrats agreed that the patient should be in a terminal state.
- The government parties sided for legalising euthanasia. Both Christian Democratic parties sided against. They chose for a construction in which euthanasia was in principle forbidden but could be accepted in the case of a legally defined so-called 'state of necessity'.²⁵
- The government parties wanted a living will for patients who a) were no longer conscious and for whom b) there was no means of restoring consciousness and who c) suffered from an incurable disease. The Christian Democrats rejected any form of living will.
- The parties in government saw ethical consultation with a patient asking for euthanasia as unworkable because this would result in an 'ethical tribunal'. The Christian Democrats in contrast said that ethical consultation beforehand is essential, stressing that it was about giving support to doctors and patients.
- The majority parties saw palliative care as an option for the patient alongside euthanasia. The Christian Democrats thought it should always be tried before even considering euthanasia.

Notwithstanding the commitment to an open and comprehensive debate, the presentation of the compromise proposal was coupled with strong statements in the media. The governing parties, so they said, were prepared to have a discussion with the opposition but the matter had to be rounded off in the Senate by mid February 2000, thus just seven weeks later. One must also remember that the Christmas recess came in the middle of that period. To the comment of a journalist that a discussion was not possible in such a short time-span, came the answer that the opposition parties were quite free to introduce amendments in the meantime. The leader of the Flemish Socialist faction in the Senate made no disguise of her dislike of the years when the Christian Democrats had held power. 'The Christian Democrats have blocked discussion on this issue for years, we must finally now have legislation.' Her Liberal counterpart let it be known that 'we have been talking about euthanasia for years. Those who do not understand it now, never will'. That the politicians of the governing coali-

25 The Belgian Christian Democratic position can therefore be compared to a large degree with that of the Dutch situation on euthanasia between 1993 and 2001, which actually came about on the initiative of the Dutch Christian Democrats.

tion did not intend to get into too serious a debate on the issue may also appear from the fact that regarding content the gulfs between the proposals of the governing parties were as wide as those between the majority parties on the one hand and the Christian Democrats on the other hand. Despite this, the governing parties easily arrived at a compromise.²⁶

The parliamentary procedure

In the period January/February 2000 a number of interesting developments took place. Cracks developed in the majority front. Among the Flemish liberals this apparently amounted to contentious differences of opinion between the factions in the Senate and Chamber of Representatives. There were also differences among the French-speaking Liberals in which the Chairman of the Senate played a leading role. He regularly let it be known that according to him it was not a majority bill that was being discussed but rather a bill from a few individual senators of the governing parties. There were likewise big differences of opinion in the Socialists parties and the Greens. The chairman of the Flemish Socialists, for example, declared himself prepared to come to an accommodation with the Christian Democrats, but was dragged back by a number of his party colleagues. These efforts towards rapprochement were also disparaged by his French-speaking colleague who suggested that an ethical debate with or without the Christian Democrats was like riding in a Fiat 500 or a Porsche respectively.

Notwithstanding a desire to make headway, the Senate Committee that was handling the Bill, began hearings with experts between February and May 2000. A wide range of persons from a cross section of professional and ideological backgrounds was invited to give their opinions. Many senators of the majority parties initially opposed these hearings ('society has waited long enough for legislation, it has finally to happen') until growing societal protest forced these hearings on them. But even afterwards the majority parties showed no real intention to proceed to an open debate on the issue with the opposition. However, on 7 July 2000, the Chairman of the Flemish Socialists reacted positively to an invitation by the Chairman of the Christian Democrats to exchange ideas on euthanasia. 'Speaking as a sociologist, society does not change because the law changes. The law follows social evolution. Ideology is thereby not a question of majority or minority. A broad discussion of euthanasia aimed at as wide a majority as possible will influence future approaches to ethical thinking'. A Green senator likewise asked for changes in the Bill to accommodate the point of view of the opposition. The chairman of the Flemish Liberals, however, reacted negatively to the invitation to enter a debate on the issue.

Meanwhile in the autumn of 2000 the British medical journal *The Lancet* published the results of research into end-of-life decisions in medical practice

²⁶ There were obviously also important ongoing differences between the bill of the governing parties and the opposition.

in Flanders.²⁷ This was an extended follow-up of the before mentioned 1998 pilot study. The new study affirmed the assumptions that euthanasia had a place in the Flemish medical world, but what was most striking was that the incidence of death as a consequence of euthanasia formed barely the tip of the iceberg: euthanasia occurred in 1.1% of the total number of deaths examined. Related treatment such as assisted suicide and the direct ending of life without a request from the patient occurred in 0.1 and 3.2% of the researched deaths respectively. It appeared that in 39.3% of the deaths concerned, medical decisions had been taken that influenced the death of the patient, 18.5% of which were due to pain relief with life shortening effects, and 16.4% to decisions to stop treatment. Seen quantitatively the occurrence of death as a result of pain relief and the absence of treatment was thus a much larger group than cases of euthanasia and assisted suicide. From a qualitative point of view it is striking that consultation with another doctor took place in less than half of all cases of euthanasia or assisted suicide and that in the majority of end-of-life decisions no discussion had taken place with the patient. Even after these figures were made known, parliamentary discussion on new legislation still focused almost exclusively on euthanasia.²⁸ Other clinical end-of-life decisions were and still are not discussed despite the repeated pleas for the contrary and despite research results that indicate they should be.

In terms of publicity, the parliamentary year 2000-2001, was more quiet than the year before, despite the almost weekly meetings of the Senate Committees dealing with the bill. Societal debate was also put on the back burner. Positions appeared fixed, what had to be said had been said. The political majority once more set a time limit. They wanted the bill to be completed before the end of the calendar year 2000. This ambition was quickly adjusted several times. First, there was talk of getting the whole legislation completed by that time, then of it passing the Senate stage and finally of the Committee finishing its work. Nevertheless discussions on the majority bill in the Committee started only in December 2000 and lasted until March 2001. There were a huge number of amendments (hundreds), which led to nightly gatherings of the Senate Committee. Opposition amendments were systematically rejected or voted against even when they concerned only simple linguistic changes. The Senate Committee finally approved the bill in March 2001. It was in large measure due to the Chairman of the Senate Committee, a Senator of the French-speaking Greens, that the speed argued for since the beginning of parliamentary debate by a number of members of the political majority was thwarted.

Since December 2000 the bill of the political majority has undergone a number of changes compared to the proposal for a bill that was introduced at

27 Deliens, L. et.al., 'End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey' (2000) 356 *The Lancet*, 1806-1811.

28 The study was published in the autumn of 2000, but the findings were made available for the parliamentary discussion although in limited form in the spring of 2000.

the end of December 1999.²⁹ One interesting change relates to the fact that in the original proposal euthanasia was no longer punishable by the Penal Code itself. In the final version in the Senate Committee the Penal Code remains unchanged and it is the bill on euthanasia itself that determines under what conditions euthanasia can no longer be considered a crime. More importantly a distinction between terminal and non-terminal patients has been introduced: in the case of terminal patients the advice of a second doctor on the medical condition of patient is needed. In the case of non-terminal patients however, also the advice of a third doctor is obliged and there should moreover be a month between the first request to end life and carrying out this request. Also the way in which euthanasia is to be controlled has been changed, and in addition the three original majority bills (on euthanasia, palliative care, and an evaluation committee respectively) are combined now. Finally, a number of adjustments have been made to the so-called living will. The bill as now presented is undoubtedly also meant to accommodate the opposition within the government coalition.

The last political development worthy of note came from the Chairman of the Senate, a Walloon Liberal, who as mentioned earlier has serious ethical doubts about the bill. In March 2001 he used his authority as Senate Chairman to ask the Belgian Conseil d'Etat³⁰ for advice about the bill. Initially the majority faction leaders were shocked by this action. The Advice of the Conseil d'Etat appeared at the end of May 2001. Hardly any suggestions were made by the Conseil that could cause a draw-back in the legislative process. The Conseil seemed cautious to interfere with this politically sensitive issue.

At the moment the bill awaits the vote of the complete Senate, which should take place some time between October and December of the parliamentary year 2001-2002. It is expected to approve the bill. After this the bill in question will pass to the Chamber of Representatives. It is difficult to predict what will happen at that point. If the Chamber passes the bill exactly as approved by the Senate then it becomes law. If the Chamber introduces further changes (either large or small, and at least a number of small changes are expected), then the law has to be returned to the Senate, which is then required to deal with it again. If the Senate is in agreement the bill becomes law, if not then it is the Chamber of Representatives that has the final say and indeed may definitively approve the bill.

To summarise the above, there is currently a strong polarisation in the euthanasia debate in Belgium. The new governing parties do not appear willing to enter into a debate with the Christian-Democrat opposition. This is understandable in the sense that, as I have tried to show above, until well into the 1990s this group was not prepared to develop legislative activities on the topic

29 The general drift has however not changed since the opportunities to carry out euthanasia are still made dependent to an important degree on unbearable (physical or psychological) suffering of the patient.

30 The Conseil d'Etat is in Belgium the supreme court in administrative cases, and can also function as a legal advisory organ on proposals for legislation.

(which is different from not talking about it!). The position of the Christian-Democrats can certainly be criticised from a democratic point of view, but nonetheless Belgian society was probably not ready for legislation until the middle of the 1980s. Indeed in this respect, certainly also in liberal political circles, doubts still exist about the desirability of an ethically liberal legislation on euthanasia.

3. Evaluation and Final Conclusions

Considering what has happened so far and bearing in mind developments in the neighbouring Netherlands, one might ask: How was it that certain factors and actors in the Netherlands made it possible for euthanasia to be a relatively early subject for social debate and regulation, and what can explain the differences between Belgium and the Netherlands in this respect?³¹ In comparing the two one must also remember that from a more global perspective the Netherlands has been exceptionally early with the acceptance of policy and legislation on euthanasia.³²

Let me first list a few notable differences between both countries.

The introduction of legislation has taken place over a shorter time span in Belgium than in the Netherlands and has in Belgium to a large extent been a parliamentary process. Legal change in Belgium appears to coincide with a relatively short parliamentary process. In the Netherlands the process of legal change has been much more gradual. It seems more to be accompanied by a societal process of discussion and consensus over euthanasia.

In Belgium the absence of the medical profession in the political discussion on euthanasia has been very striking. In the Netherlands the medical profession has been very present in the societal and medical debate on this issue.

In Belgium both the public prosecutor and the courts have remained absent in developments of legal norms regarding euthanasia. In the Netherlands both these parties have played prominent roles in the development of legal norms.

There is however one striking similarity with regard to the development of legislation: in both countries a parliamentary bill has only had a chance when the Christian-Democrats were no longer part of the government.

The explanation for the first difference is, I believe, mainly due to the societal and political influence of catholic thinking that has long been able to continue in Belgium. This has led to a situation of denominational segregation

31 See for the development in the Netherlands Weyers in this issue. Also Griffiths, J., Bood, A. and Weyers, H., *Euthanasia and Law in the Netherlands*, Amsterdam, Amsterdam University Press (1998), 382 p.

32 Meanwhile the majority of the Belgium population seems in favour of regulation of euthanasia. An opinion poll in October 1999 commissioned by the daily newspaper *La Libre Belgique* showed that 80% of Belgians supported legislation for euthanasia under specific circumstances. Questions about the specific contents of such a bill were not asked. It also appeared that barely 10% of Belgians were radically against any form of euthanasia, and that 10% did not think any form of legal restriction was necessary.

in Belgium. Whereas in the Netherlands the influence of Christian thinking already disappeared in society, however not necessarily politically, in the 1960s, this was not the case in Belgium. An important reason for the most powerful denomination, the Catholics, maintaining its influence after the 60s is that it did not, as in the Netherlands, have to compete with Protestantism. As a result secularisation came about later in Belgium than in the Netherlands. Christian catholic thinking has thus been able to continue to exercise societal and political influence. Using its political wing as mouthpiece, the catholic denomination wanted to prevent legislation on euthanasia. Since they took part in the government coalition this proved to be successful.

Today a significant part of the societal base that supported denominational segregation in Belgium has fallen away. Desegregation in spirit is for a whole number of people a fact. There are also signs that institutional denominational segregation is likewise beginning to wane. For example, the pillar organisations in Flanders no longer always have political influence as they had before, and the daily press is no longer the mouthpiece of political parties. Whatever the case, there is no longer any societal base for militant Catholicism. Also in the 1990s, within Christian Democracy people were beginning to understand and appreciate that if they wished to act as a broad centre party, then they must adopt a more tolerant position on ethical matters. In the light of this, it is not surprising that from the middle of the 1990s in Belgium, while the Christian Democrats were still in government, political discussion on euthanasia likewise began to have a chance. This was perhaps also the main reason why a positive political dynamic was able to develop around the Advice of 12 May 1997 of the Advisory Committee on Bio-ethics.

Concerning the second point of difference: whereas in the Netherlands the Royal Dutch Medical Association (KNMG) early on encouraged openness from the doctors concerning euthanasia and thus provided the judiciary with a chance to play a role in developing rules, the professional medical associations in Belgium appear not really willing to exercise influence on the legislative process. Thus the Belgian Medical Association argues that euthanasia is an issue better wholly left to the professional class itself. In the spring of 2000, the vice-chairman of the Association explained, during the previously mentioned hearings in the Senate, that 'the Medical Rules of Conduct have solved many of the problems. The Medical Association is neither for nor against legislation but neither is it asking for it'. When asked whether legislation would not provide doctors with more legal protection, he replied 'that is relative, can you cite the most recent conviction against a doctor for carrying out euthanasia? I know of none. Abuse exists but you are not going to alter that through softening the law'.

I see two reasons that may explain the differences between Belgium and the Netherlands on this issue. In the first place the Dutch Medical Association is supported much more from the base than is the case for the Belgian Medical Association. For example: in Belgium the controversy over obligatory mem-

bership re-surfaces from time to time and many doctors complain of a lack of democratic consultation in the Association. On euthanasia there is also a split between the professional association and significant parts of the base, which makes it impossible for the Belgian Medical Association to take a united view. In the second place, the absence of the Association in societal and political discussion on euthanasia is also no coincidence as it is only responsible for medical discipline and the administration of registration and such matters. Hence, as an organisation not established in the classic denominational pattern, the Belgian Medical Association had, and still has, not only far less direct access to politics via the classic denominational organisations, but has also never been able to speak for all its members with one voice. The different perspectives found within the Association are thus explicitly divided, which makes it difficult to exercise any political influence.

With regard to the non-involvement of the Public Prosecutor and the Courts on this issue, I have no conclusive explanation. The absence is all the more striking since in the context of abortion the Public Prosecutor pursued a vigorous policy indeed. From a more global perspective it is striking that in general abortion was rapidly legalised in many western countries, but to date legislation on euthanasia is unique to the Netherlands. Maybe this difference has to do with the development and influence of feminism and women's movements since the 1960s and 70s, which made abortion one of their points of action. Whatever the reason for this difference, no case law on euthanasia exists in Belgium. Social and political discussion is therefore not legally pre-structured, which in part can explain why the euthanasia debate in Belgium is of a strong parliamentary nature.

Postscript: Senate approved the Bill

On 25th October 2001, the Belgian Senate approved the bill of the political majority.³³ In the final and plenary debate 136 amendments were still introduced, mainly by Christian Democrats. None of them was approved of. The final vote on the bill, up to a large extent represented the division between political majority and opposition. Of the 75 members of the Senate, 68 members were present at the time of the vote: 44 approved of the bill, 22 voted against, two members abstained from voting. Of the political majority three French-speaking liberals voted against, two members, one French-speaking liberal and one member of the French-speaking Green Party respectively, abstained from voting. Of the opposition no senator approved of the bill. It is expected that the political discussion in the Belgian Chamber of Representatives will start soon.

33 Document nr 2-244/23 of the Belgian Senate, session 2000-2001, 9 July 2001.

New Life in the Assisted-Death Debate in the US

Scheduled Drugs v. NuTech

Margaret P. Battin

1. Change in the Issue of Physician-Assisted Suicide

In the years since Dr. Jack Kevorkian went to jail, public involvement with the issues of physician-assisted suicide and active euthanasia may seem to have subsided. Front-page stories less frequently raise the question; debates on talk shows have turned to other social issues; there seems to be less volatile, less frequent, less consuming public debate about hastened death and the right to die. Many other countries have been concerned with end-of-life issues – Canada, the Netherlands, Britain, Australia, Switzerland, Belgium, the Scandinavian countries, and others – and in some of them the debate seems to be in decline, but I think the change is most evident in the United States. The assisted-death debate may seem moribund, if not nearly completely dead.

Some of the apparent decline in the American public's interest in issues about physician-assisted suicide and active euthanasia may be attributed to the disappearance of Kevorkian from view – after all, 'Dr. Death', as he was often called, was a master at knowing how to arouse the interest of the media. Now in prison on a sentence of 10-25 years, he is no longer even allowed to talk to the press in person. However, I think something else is at work as well. The dispute over hastened death is evolving, mutating, in a way that lends itself less easily to public debate, but at the same time is far more vulnerable to political manipulation. It is this current process of mutation in the debate, evident in the strategies of both proponents and opponents of legalization, that I want to explore here. While this process is occurring in many countries, I think it is most pronounced in the comparatively adversarial legal climate of the United States. I do not think the assisted death debate is dead at all. I shall focus particular attention on the ways in which new strategies of political and legal activism on both sides are tending to escalate the debate, taking it first from populist appeals to state-law initiatives and counter-initiatives, and then from state-level to federal-level manoeuvres.¹ But this pattern is hardly complete. The opportunity for reasonably stable compromise seems to have failed, and the debate now stands at what may be an even more charged and polarized point than at any earlier moment, albeit more out of public view. It is the point, I think, at

¹ Not all observers see this pattern in quite the same way, and I'd like to thank Charles Baron – who sees it somewhat differently – for his response to this paper. I'd also like to thank Russel Ogden for his comments as well.

which the entire model of approach to end-of-life issues in the United States could change, even as the U.S. yields to pressures for greater liberalization, and it is not clear that this would be a change for the better. Yet while there is reason to think the situation could get still worse, there is also some slight reason, as I shall suggest, to imagine that it could take a turn for the better instead.

2. Political Escalation

Concern with end-of-life issues began to arise in the United States in the late 1960s and early 1970s, in part as a product of the civil-rights and rights-favoring movements that spoke not only for African-Americans but also for other disfavored groups: women, people from religious minorities, people with disabilities, and so on. Among those seeking to gain recognition of a larger range of rights were medical patients – people with illnesses, injuries, or other reasons for involvement with the health care system, and in particular people with terminal illnesses.

Some of the rights secured by patients with terminal illnesses were informally recognized rights established in professional practice, like the right to know one's diagnosis – something nearly universally withheld in the 1960s, but now nearly universally provided, at least in the U.S. (though not for example Russia, Greece, or Japan). Many other sorts of rights pertaining to patients, especially patients with terminal illnesses, were legally codified – sometimes in legislative action, sometimes as a result of court decisions, but almost always with considerable social and legal dispute. Over a long period of years, patients, especially patients with terminal illnesses, sought and won not only the right to full information about their conditions and prognoses but also the right to refuse treatment, to discontinue treatment, to specify in advance what treatment they would and would not accept if they became incompetent, and to insist that they be treated only with their explicit, advance, or, in emergencies, implied consent.² Gradually the issues that came to light at the time of the passage of the California Natural Death Act of 1976, the first of the living-will statutes establishing a patient's right to stipulate before the onset of incompetence treatments he or she wanted to refuse later on, developed into a fullblown dispute over the issue of direct control of the process of dying. This was the foundation, the floor, so to speak, from which has emerged a pattern of continuing escalation in the political disputes over physician-assisted suicide.

2 See the historical account in Norman L. Cantor, 'Twenty-Five Years After *Quinlan*: A review of the Jurisprudence of Death and Dying', (2001) 29(2) *Journal of Law, Medicine & Ethics*, 182-196.

2.1 Populism and its alternatives

It was around this time, in the late 1970's and early 1980's, that back-and-forth political volleying over the issues of assisted dying, including physician-assisted suicide and active euthanasia, began in earnest. To be sure, the issue had been percolating for many years. But the first real efforts of proponents of physician aid-in-dying – including both those who believed that these practices should be recognized as ethically acceptable and those who believed they should be legalized – came as an effort to sway public opinion.

This was the first new step of what would be a long series of further escalations. There were many contributions to the effort to bring the issue of assisted dying to public attention, but perhaps the most visible of the early proponents of moral legitimization and legalization was the British journalist, Derek Humphry, whose frank book *Jean's Way* described his own role in assisting the suicide of his first wife as she was dying of cancer. Humphry followed this with an a second populist move, the establishment of the Hemlock Society (1980), a grassroots organization of people interested in personal choice for themselves in the matter of dying and with the legalization of such practices. Still later, Humphry made a third, perhaps even more effectively populist move: not only did he bring to the public instructions for using an ordinary plastic bag to bring about death, but in 1991 he published a book of hitherto professionally restricted information crucial in assisted suicide: the how-to manual *Final Exit*. This little book provided concrete, explicit factual information about lethal drugs to the terminally ill, a move so effective in reaching the public that the book hit the top of the *New York Times* bestseller list and its title became a household phrase.

Humphry wasn't the only writer to address the public at large; a variety of novelists and memoir-writers had also been exploring personal experiences in the matter of the right to die, including Lael Tucker Wertenbaker, Jessamyn West, and Betty Rollin. During the same period Jack Kevorkian M.D. also played to the public, exhibiting his considerable capacity to keep the issue of physician-assisted suicide before the public view: he made sure the press was called when the people he had assisted were found dead in Volkswagen buses motel rooms, and the like. These early moves in the disputes over the right to die had the effect of escalating the debate by first bringing the issue out into the open, primarily by portraying a series of heartrending personal cases, then – still drawing on these cases – by establishing a constituency committed to change. Perhaps most important, it made crucial information public; now there could be no turning around.

Opponents took their case to the public too, though they used a quite different strategy. They also tried to appeal to the public through personal memoirs, interviews with the press, and by developing grassroots organizations, but they more frequently worked through or in concert with existing organizations, especially the Catholic Church, Hospice, disability rights groups, and the AMA, the authoritative American Medical Association. Opponents of assisted dying

urged these groups to take stands against legalization and/or to articulate their stands more forcefully and broadly. This strategy, while it also served to intensify the debate, had the advantage of suggesting that the bulwark institutions in society were opposed to expansions in the right to die, and that indeed society would be undermined if aid-in-dying legislation permitting physician-assisted suicide or euthanasia were allowed to pass.

2.2 State-level legislation

The next escalation in the dispute occurred in the mid-to-late 1980's, as proponents sought change through state-level legislation to make physician-assisted suicide legal.³ Proponents understood physician-assisted suicide largely in the 'arm's-length' sense, favoring changes in the law that would permit a physician to provide his or her terminally ill patient who so requested with a prescription for a lethal drug. Proponents worked to bring referenda before the voters in a number of states, and succeeded in putting it on the ballot in Washington (1991), California (1992), Oregon (1994), Michigan (1998), and Maine (2000). This was an attempt to change not just public opinion, but the law.

There were victories and losses for both sides in these events; every step of the way was contested, in a pattern of what Robert Kagan and other commentators have called 'adversarial legalism'.⁴ Referenda failed in Washington, California, Michigan, and Maine, though in several of these states by very narrow margins. However, Oregon's initiative known as Measure 16 passed – indeed, passed twice, first by a very narrow margin in 1994 and again in 1997 as the Oregon legislature returned the measure to the ballot box for a second vote, where it passed the second time by a much wider margin.

At each of these junctures in each state, but especially in Oregon, the tension between proponents and opponents increased, as did the amount of money flowing into campaign chests. The playing field had changed: though appeals to public opinion remained important, as they had from the outset of this debate, the real contest was now the battle for state law. There was no longer, if there ever had been, any sense that an influential, centralized governmental or moral authority could make policy acceptable to both sides, and the dispute even more adversarial and politically charged.

2.3 Federal-level activity

Concurrently, a further escalation in the ongoing battle was also taking place, upping the ante still further, so to speak, to a new, federal level: in an effort to

3 By this time concern with active euthanasia had largely dropped out of the picture, and most of the referenda included no provision for it.

4 See Kagan, R.A., *Adversarial Legalism: The American Way of Law*. Cambridge, Massachusetts, and London: Harvard University Press (2000).

secure civil rights in courts that couldn't be attained legislatively (a strategy much like that which proponents of contraception and abortion had used), proponents succeeded in bringing a pair of cases, *Washington v. Glucksberg* (9th Circuit) and *Vacco v. Quill* (2nd Circuit), before the U.S. Supreme Court. The Court's ruling in these cases, handed down in 1997, held 9-0 that the state statutes in question in Washington and New York – statutes prohibiting assistance in suicide in general, without specific reference to physician-assisted suicide – were constitutional. Opponents claimed they had won the day: the high court had said there was no right to physician-assisted suicide. Proponents pointed out, however, that the court had made it clear that states could adopt laws criminalizing assisted suicide if they wished, but that they could also refrain from adopting such laws or, in adopting them, could make an exception for physician assistance in the circumstances of terminal illness. Thus it would be equally legal, proponents reasoned, for a state to leave the issue of physician-assisted suicide open, as several states did, or to legalize it, as Measure 16 had done in Oregon. Indeed, there was reference in the Supreme Court's decision to the prospect of a 'laboratory of the states' in which some states might legalize physician-assisted suicide while other states hung back, so to speak, to see how it would go.

3. Interlude: The Failure of Compromise

This picture, I think, shows us the moment in which real compromise between opponents and proponents of assisted dying might have been possible, and in which the series of escalatory moves – each upping the ante to a new level – might have ceased. This was the picture in which one state, Oregon, was willing to try legalized physician-assisted suicide, under a series of careful controls and with state-mandated reporting, but the other 49 states either had no law (as was the case in just a handful) or (like the vast majority of states) prohibited assisted suicide. This was the picture the Supreme Court's decision almost seemed to recommend: opponents could hold the forces of change at bay, since physician-assisted suicide would not be legal in 49 out of 50 states, but proponents (and the entire country) would have the opportunity to see how such a practice might function where it had become legal. If it were legal, would there be only defensible, controlled use, free from pressures of all sorts? Or would it lead to the abuse of vulnerable patients, as both opponents and even some proponents feared? Time would be allowed to tell, and in those states where physician-assisted suicide was not legal – that is, almost all of them – such already-legal measures as the heavy use of opiates under the principle of double effect and recourse to terminal sedation could still be used in the most difficult cases.

Of course, such a 'compromise' did not satisfy real advocates of the right to assistance in dying, since it left dying people in 49 out of the 50 states without recourse to active help. Nor did it satisfy opponents either, since it accepted

actual legalization, even if only in Oregon. It was just a compromise, not even a negotiated compromise but one emerging from contrary political pressures. Yet it still might have seemed a desirable compromise, since it both remained open to further evidence about the effects of legalization and yet was given some limited validity by the Court's intimation that it would accept either further legalization by additional states or an end to legalization in the one state that had granted it.

But the political reality has, in the few years since the Supreme Court's decision, turned out to be quite otherwise. Despite some academics' and physicians' attempts to frame conciliatory positions, and despite real agreement among many parties on the importance of better techniques of pain control and greater access to pain management, there does not appear to be a stable political compromise emerging at all in the social and legal debates over assisted suicide, but rather, continuing political hostilities and further escalatory moves. Better pain management is not the only answer; the dispute is still fueled by issues about personal vision and control.⁵

4. Escalation, Continued: The PRPA and NuTech

Seeing Oregon as the hole in the dike – the domino that would let many others fall – opponents sought from the moment Measure 16 first passed in 1994 to undercut it. The first attempts were pursued at the state level, a complex series of legal maneuvers challenging the referendum at every turn, delaying implementation so long that the Oregon legislature finally ordered the second vote. However, with the final implementation of Measure 16 as law in November 1997 (three full years after its original passage in 1994), opponents turned to a new tactic, seeking to scuttle Oregon's law by changing federal regulations. This move too further escalated the dispute.

Their first effort was to have the federal executive branch, specifically the Justice Department, override Oregon's law by preventing physicians from using scheduled drugs for 'nonmedical' purposes. Attorney General Janet Reno rejected this move, and opponents then turned to a congressional measure. This second effort, pursued first under the label *Lethal Drug Abuse Prevention Act of 1998* and then as the *Pain Relief Promotion Act of 1999* (PRPA), sponsored by Rep. Henry Hyde and then also Sen. Don Nickles, was a measure that would amend the Federal Controlled Substances Act. The revised Act would 'prohibit the dispensing or distribution of a controlled substance for the purpose of causing, or assisting in causing, the suicide or euthanasia of any individual'. It would not make physician assistance in suicide illegal; instead, it would make illegal the use of scheduled drugs for the purpose of causing death. Thus, the very drugs that make it possible for physicians to induce a

5 See my 'Physician-Assisted Suicide: Safe, Legal, Rare?' in *Physician-Assisted Suicide: Expanding the Debate*, Battin, M.P., Rhodes, R. and Silvers, A. (eds.), New York and London: Routledge (1998) 63-74.

painless death without unwanted side effects like hallucinations or convulsions – the barbiturates and related drugs – would be unavailable to physicians; penalties for violations could range from loss of practice privileges at specific hospitals to a federal prison sentence of up to 20 years. Since the effect of Oregon's Measure 16 was precisely to allow physicians to legally give patients a prescription for lethal drugs, the PRPA would effectively gut Measure 16 and – this is the specifically escalatory feature – any similar law that might pass in any other state in the future. Lesser measures, like triplicate prescription laws, computer-based prescription tracking, and state limitations on maximum doses of morphine, have something of the same deterrent effect. Although the most recent version of the PRPA died without action at the end of the congressional session in 2000, partly because of opposition from palliative care specialists who pointed out that it would impair good pain relief in all 50 states, rumors grew widespread that the Bush administration – which opposes physician-assisted suicide – planned to issue an executive order with the same effect as the PRPA. Only the unexpected shift in control of the Senate from Republican to Democrat, as well as the distraction by the 'war on terrorism', seemed to stall this move, but in early November 2001 – just as this paper goes to press – the Attorney General, John Ashcroft, acted.

Even before this escalatory move by opponents had actually taken place, it had already elicited a further escalatory counter-move from proponents. Proponents (correctly) viewed the PRPA and subsequent federal efforts to restrict scheduled drugs as directly aimed to undercut their gains so far, gains made in the arduous and expensive process of bringing one referendum and then another, and another, onto state ballots. What they needed was a strategy that could not be vetoed by a federal-level tactic like the PRPA, which at one blow had raised the threat of erasing all their careful state-level work so far *and* precluding any such efforts in the future. Indeed, the PRPA and similar moves threatened even the quiet underground of physicians willing to help patients ease into death in a discreet way, since it would permit new surveillance of their activities. Some activists among the proponents – though not all – thus turned to a new sort of strategy. This new strategy involves the development of *non-medical* means of bringing about death, means that are not subject to the restrictions imposed by the PRPA. Ironically, this move represents a return to a broad-scale, populist approach, reminiscent in certain ways of the early days of the right-to-die movement.

What proponents are developing as a response to the PRPA and similar federal measures that are intended to undercut state law legalizing physician-assisted suicide is a series of methods of producing death that can be employed without the assistance of a physician and without prescription-controlled drugs, though they will still assure a gentle, easy death. These techniques are generally referred to as 'self-deliverance new technologies', or 'NuTech'. Under development by a group of researchers known as 'the engineers', especially centered in the Last Rights Publications group run by John Hofess, with support from Hemlock, from Derek Humphy's organization Ergo!, and from

Philip Nitschke's Voluntary Euthanasia Research Foundation in Australia, NuTech involves a range of devices using a variety of mechanisms for causing death or, as NuTech supporters put it, 'deathing' (like 'birthing').⁶ These include a customized plastic bag (the 'Exit Bag') and a variety of delivery devices for various inert gasses, like helium, argon, and nitrogen, which have the effect of reducing the oxygen concentration in air and so causing asphyxia. Among the devices is a hypoxic tent (known as the 'Exit Tent'), available in a one or two-person model, which uses the same techniques athletes use for reducing oxygen – that is, mimicking high-altitude training – but lowers the oxygen content to fatally low levels. Similarly, an apparatus known as a 'De-breather' uses scuba technology to recirculate breathed air and so slowly reduce the oxygen level. Also under development are the use of toxic plants that are not federally scheduled, like hemlock (used in the execution of Socrates), various veterinary euthanatics, and certain poisons.

This new move, the development of NuTech for use in suicide by terminally ill patients, still further escalates the dispute over physician aid in dying by taking the issue out of the hands of physicians altogether. None of these devices are illegal; indeed, anyone can buy a tank of helium, usually sold for inflating party balloons. The very purpose of NuTech is to develop 'nonfelonious' ways of bringing about death, as Derek Humphry puts it, a 'new technology for legal acts of selfdeliverance'. While not illegal, these new technologies also leave little postmortem evidence on the body, so that if the devices themselves are disposed of effectively by friends or family members, the circumstances under which death occurred remain relatively secret.

Thus NuTech, responding to the PRPA's attempt to gut Oregon's law legalizing physician-assisted suicide, in effect undercuts the intent of the PRPA: it circumvents the need for scheduled drugs, and by taking physicians out of the picture altogether, renders irrelevant any attempt to restrict what their intentions may be in prescribing drugs. The PRPA was intended to make it illegal for physicians to prescribe the drugs typically used in assisted suicide for the purpose of causing death, and thus to gut any state law that might legalize physician-assisted suicide, even though the Supreme Court had clearly intimated that such laws could pass constitutional muster. NuTech moves outside this picture altogether. It tries to do so by moving beyond the guns, ropes, bridges, razor blades, sleeping pills, and high buildings people have traditionally used for suicide by providing methods seen as less violent and more humane, but where control is still retained by the person in question. The PRPA was intended to gut Measure 16; NuTech aims to utterly disempower the PRPA and more recent moves like it.

To some observers, the various devices under development as NuTech seem ghoulish. The debreather involves a face mask placed over the nose and mouth of the patient. The Exit Tent is a closed space, somewhat like a back-

6 For an account of NuTech devices, see Ogden, R.D., 'Non-Physician Assisted Suicide: The Technological Imperative of the Deathing Counterculture', (2001), 25 *Death Studies*, 387-401.

packer's camping tent, rolled out on a bed or on the floor. The helium delivery system presents a difficult three-way tradeoff between technical reliability, privacy, and low cost: while a 'party tank' of helium for filling balloons costs about \$22 and can be purchased anonymously, it lacks a flow control mechanism; a professional high-pressure helium tank with a regulator not only requires registration for purchase but costs some \$260.

Opponents have called these devices 'human-zappers', like insect-zappers,⁷ and many have pointed out the association with Nazi euthanasia practices that gas machines seem to evoke. Not all proponents of physician-assisted suicide support NuTech, and many of the more centrist organizations supporting legalization have shied away from it, insisting that what they seek is a change in the law to make physician-assisted suicide legal. Supporters of NuTech agree that it would be better to have *physician*-assisted suicide legalized and readily recognize that patients would rather have an oral drug, a simple, side-effect-free drug that could be taken easily without gadgetry and would ensure a gentle, painless death – but they point out that this is exactly what the PRPA or any federal-level administrative edict restricting scheduled drugs would render impossible. It is in this way, they say, that the disputes over aid-in-dying have been irrevocably altered. If patients cannot have legal physician-administered aid-in-dying, they must be able to do it for themselves.

NuTech is not yet widespread, if it ever will be, though by late 2001 over a hundred cases had been reported.⁸ A few observers think that because NuTech is more immediately and reliably efficacious in producing death than oral medications, it will be preferred to barbiturates or other drugs, and they insist that it is not unpleasant: after all, as high-altitude climbers know, lack of oxygen produces euphoria. They also point out that because its use is hard to detect, families can be more directly involved. Derek Humphry has already issued a 'Supplement to *Final Exit*' describing the use of helium inhalation and plastic bags. However, among those who support legalization, the more centrist groups continue to press for state-level and – as a long-term strategy – Supreme Court legalization of physician-assisted suicide.

It is far too early to tell whether the pattern of mutual escalation reflected in the PRPA and its successors and in NuTech will be the shape of the future – the next Supreme Court case that now seems inevitable will perhaps determine this – , or whether the current picture of polarization and politicization represents a transitory blip of extremist but peripheral moves by both sides in an otherwise relatively smooth pattern of development towards eventual political and legal consensus. At the moment, the issue is whether any new sort of compromise could emerge.

7 Jonathan Imbody, 'Euthanasia Supporters and their Strange Inventions', *Washington Times*, Saturday, Nov. 20, 1999, Section: Commentary, Editorials, Letters, A12.

8 Russel Ogden, personal communication.

5. Is a New Compromise Possible?

Although this goal has so far proved elusive, NuTech engineers are also working to develop a ‘suicide pill’ that a patient could synthesize in the privacy of his or her own home out of readily available, nonrestricted ingredients that could not be banned. This is something quite far beyond the so-called ‘Drion pill’ being discussed in the Netherlands, a hypothetical euthanatic drug named after the former member of the Dutch Supreme Court who launched a much-discussed proposal about it.⁹ Unlike the Drion pill, the pill that the NuTech engineers envision – this is its particularly important feature – would be self-compoundable. A suicide pill that could be synthesized at home out of easily available ingredients would give terminally ill patients irrevocable control over their circumstances by making them able to end their lives as they choose, the NuTech engineers point out, without being dependent on physicians for assistance in doing so. Nor would patients violate state or federal regulation in ending their own lives, since suicide itself is not illegal – though, of course, if interrupted in the act, they may be judged a danger to themselves and involuntarily committed for mental health treatment.

If an oral euthanaticum of the self-compoundable NuTech sort were developed and information about it widely and publicly promulgated, this might seem to complete the series of escalating moves begun in the early days of the right-to-die disputes. Somewhat ironically, the development of a NuTech ‘suicide pill’ recipe that could be compounded by the user him or herself would in some ways resemble a return to the populist move that Humphry’s publication of *Final Exit* involved – a populist move designed to put information, and thus control, into the hands of patients. But it goes a great deal further: *Final Exit* provided information about drugs which still required a physician’s prescription to obtain; the new NuTech do-it-yourself suicide pill would eliminate this dependence on doctors, pharmacies, and state and federal prescription regulations altogether.

This might seem to produce the conditions for yet another compromise. NuTech would make an easier way of ending life available to dying patients who wanted it, and the proponents of assisted dying would see the central objective of their campaign achieved. At the same time, opponents would see one of their central objectives realized as well: to keep suicide and euthanasia – the deliberate, intentional causing of death – out of the hands of physicians. Thus both sides would win: an earlier, easier, self-controlled death would be possible, but the slippery slope that physician involvement seemed to risk, or at least most of it, could be avoided. For those whose opposition is based on slippery-slope warnings that fear legalization because it might lead to the abuse of pa-

9 Drion asked whether persons over 75 years of age, under very limited conditions, should have the right to be supplied with a medicine with which they could choose their own moment of death and thus avoid being exposed to a situation of physical or mental deterioration. See Griffiths, J., Bood, A., and Weyers, H., *Euthanasia and Law in the Netherlands*, Amsterdam: Amsterdam University Press (1998), 82.

tients by callous or overworked physicians and greedy, cost-conscious health-care institutions that control the behavior of physicians, the development of a patient-compounded, patient-administered suicide pill would place decision-making about causing death squarely with the patient, not with the physician, the nurse, the hospital, the healthcare organization, the government, or any external party; it would thus decrease pressures on the patient and hence reduce the risk of abuse by other parties, though of course it would not protect the patient from his or her own irrationality. Of course, such a compromise would indeed be a compromise, with each side losing as well: proponents would give up the right to assistance in bringing about one's own death by a physician one trusts; and opponents would have to live with the fact that terminally ill patients were committing suicide with impunity.

6. A Change in the Model of Dying?

In contemplating the possibility of such a circumstance, it is important to note the similarities and differences of such an approach in the United States to those of other nations in the developed world. In the developed world, which is now in what is known as the fourth stage of the epidemiologic transition, the majority of the population dies at comparatively advanced ages of degenerative diseases with characteristically long downhill courses: it is this pattern that presents such dilemmas about the end of life. People in the developed world tend to die at late ages (average life expectancy in the developed world is in the late 70's, in some countries nearing 80); they die of degenerative diseases (heart disease, cancer, stroke, liver, kidney, and other organ failure, rather than (with the exception of AIDS and pneumonia) parasitic and infectious diseases), and they inhabit worlds with sophisticated health care systems. There are three principal forms of response to this situation, three models of response to the dilemmas of dying in the contemporary developed world, represented respectively the United States, the Netherlands and Germany.¹⁰ All three of these countries, the United States, the Netherlands, and Germany permit withholding and withdrawing care in order to 'allow' a terminally ill patient to die rather than prolong treatment as long as possible, but the Netherlands also permits active euthanasia and physician-assisted suicide, which are now legal under a careful set of guidelines for due care, and Germany in effect allows non-physician-assisted suicide, since assisting a suicide is not illegal provided the person assisted is competent and in control of his or her own will.

Patterns of approach to end-of-life dilemmas in other developed nations resemble one of these three more or less closely. The approach taken by the

¹⁰ See my 'Euthanasia: The Way We Do It, The Way They Do It', which originally appeared in the *Journal of Pain and Symptom Management* 6(5) (1991), 298-305. It has been reprinted and updated many times in various places, to include John D. Arras and Bonnie Steinbock, *Ethical Issues in Modern Medicine*, 6th edition, Mountain View, California: Mayfield Publishing Co., forthcoming 2002.

United States in its primary reliance on withholding and withdrawing care but rejection of assisted dying is also taken by the United Kingdom and by Canada; the Netherlands' law permitting active euthanasia and physician-assisted suicide has just been followed by a similar law in Belgium; and Germany's distinctive legal situation, in which neither suicide nor assisted suicide are violations of the law and in which aid-in-dying may be provided by non-physicians, is also the case in Switzerland.

Over the last several decades, proponents seeking legalization of physician-assisted suicide in the United States have been following more or less what might be described as the pattern or model set by the Netherlands. Here, physician involvement in the process of bringing about the patient's death is central and respected: provided the guidelines for due care are met, the Dutch physician may openly and legally perform active euthanasia or may assist directly in the patient's suicide; this is now also likely to become legal in Belgium. In Germany, physicians are not accorded a direct role in causing death and would have duties to rescue an unconscious patient who was in the process of suicide; however, in Germany and other Germany-speaking nations like Switzerland, assisting a suicide is not illegal will (and has not been since the time of Frederick the Great, 1742) provided the person is competent and in control of his or her own. In Germany, suicide may be assisted, but not (according to the German physicians' code of ethics) by a physician; the primary role in assisting the suicide of a terminally ill person is instead likely to be taken by a family member, friend, or companion trained by the right-to-die society to provide such aid. The assister remains within the law in providing the means of suicide and perhaps in helping the person take it, but, because there is a generalized duty to rescue an unconscious person, cannot remain with the suiciding person after unconsciousness sets in. While the actual number of cases which take place does not appear to be high in either country, the Netherlands' picture of response to end-of-life dilemmas – in addition of course to the far more frequent strategies of withholding and withdrawing care and the use of morphine foreseen, but not intended, to cause death is one of professional, physician assistance; the picture in Germany is one of non-physician assistance or self-performed suicide.

So far, for the last several decades, all emphasis by proponents of assisted dying in the United States has been on making it legal for the physician to provide assistance to the patient. This is to follow in broad general outlines the approach of the Dutch. However, following the escalatory moves of the PRPA and the counterresponse of NuTech, the model the United States seems forced to follow in end-of-life dilemmas about assisted dying seems more nearly like the approaches set by Germany and Switzerland, where physician involvement is minimized or prohibited though a family member or friend can legally assist.

The difference between these two models, the Dutch and the German, is substantial. What is central in the Dutch picture is the interaction between physician and patient in the matter of assisted suicide: this model requires a long period of sustained consultation, so that the physician can be sure that the pa-

tient's decision is firm and stable; it expects the physician to be sure that the suffering (whether physical or psychological) is real and cannot be relieved by any treatment acceptable to the patient; it demands that the physician provides the patient with full information about his or her condition, about the prognosis, and about alternative forms of treatment; and it requires the physician to explore his or her own assessment of the situation by consulting with another physician. In Germany and other German-speaking countries with laws that do not prohibit assistance in suicide, in contrast, though apparently comparatively few patients choose this route, what is essential is independence from medical control: it may in part be a matter of the patient's search for a mode of dying – *Freitod*, or 'free death' – that is free from the negative connotations of 'suicide' and expressive of his or her own personal values, as well as a last resort when pain management fails. In general, suicide in terminal illness proceeds in Germany outside the medical establishment, though with other helpers, in contrast to the Netherlands, where it is a role willingly assumed by the medical community, even though it is often a difficult one for physicians to carry out.

The shift from roughly following the Dutch model to roughly following the German one is of substantial significance, not because it is the Netherlands that is left behind or Germany that is embraced, but because the American populace does not have the several hundred years' worth of experience (since the time of Frederick the Great) in living in circumstances in which assistance in suicide under certain conditions is not illegal. To be sure, a turn toward the use of NuTech in the United States would not make assistance in suicide legal, but because NuTech is comparatively simple, needs no physician, and leaves no telltale evidence, it might make it easy: the issue is whether the American populace is prepared for a situation in which end-of-life suicide without physician assistance is a real and socially accepted possibility. Yet whichever course is eventually chosen as a matter of public policy in the United States – the medically-oriented one more similar to the Netherlands, or the amateur, self-reliant, do-it-yourself version more like that in Germany – it is not clear whether either would serve as a final, stable compromise. Neither opponents nor proponents in the United States are likely to be fully satisfied by any compromise situation, and if they are not, the question remains whether there will be a further escalatory move that ups the ante to a still higher level.

Long gone is the possibility of what some early opponents and even some proponents said they wanted: a practice that would be available to those who really needed it, but was out of sight, under the table, discreet and quiet, not the subject of legislation. To be sure, it would only have been the privilege of patients with a physician close enough to them to be willing to take this risk; but even this privilege may be disappearing. Now, it seems, with so many escalating, polarizing maneuvers already over the dam, the only possible route seems to be further escalation.

7. A Glimpse of the Future?

What might these further escalations be? Here, I think, we go beyond evidence from the current scene, but we can imagine various new moves: for example, opponents might try to have suicide – not just assisted suicide, but suicide itself – recriminalized, as it was throughout Europe in medieval and early modern times, and in England until 1961. Of course, recriminalization would make psychiatric treatment for ‘ordinary’ suicide attempts far more problematic if these patients were also labelled criminals; any attempt to avoid this result by legally distinguishing ‘ordinary’ suicide from terminal-illness suicide, given the difficulties of prognostication and the even greater difficulties of assessing intent, would prove unworkable. To recriminalize suicide, even terminal-illness suicide, would invite such disruptive practices as greater surveillance of medical practices with high concentrations of terminally ill patients, like oncology or neurology, where, for example, prescription patterns could be monitored and outlier physicians identified. Among other things, this would cause a profound change in the relationship between physicians and terminally ill patients, precluding the possibility of discreet understandings between physicians and patients about matters of dying, and inviting substantial invasions of privacy.

On the other hand, proponents might respond with, say, conceptual initiatives in the media, press, and literature that attempted to change the cultural understanding of ‘suicide’, so that what had been opposed as physician-assisted suicide would no longer be seen – and opposed – as suicide at all. Many euphemisms have already been proposed – ‘self-deliverance’, ‘aid-in-dying’, ‘hastened death’, to name but a few, but what we might expect is a more concerted effort at both linguistic and legal redefinition. Oregon’s Measure 16, like all the U.S. referenda so far, stipulates that actions taken in accord with the Act shall not constitute suicide.¹¹ This sort of redefinition would trade on altered cultural perceptions and would have something in common with changed perceptions of, say, pain as divine punishment for human sin or revenge killing as appropriate and justified: things we for the most part no longer assume. Playing an active role in bringing one’s life to a close when one is terminally ill might no longer be seen as ‘suicide’ at all, and thus not assumed to be wrong.

Such cultural redefinition is a longterm process, but by no means impossible, and indeed may already be partly under way. In the current stage of the dispute over physician-assisted suicide, active euthanasia, and other sorts of hastened death, neither sort of new move – that which might be made by oppo-

11 The Oregon Death with Dignity Act, Section 3.14: ‘Actions taken in accordance with this Act shall not, for any purpose, constitute suicide, assisted suicide, mercy killing or homicide, under the law’. As stipulated in the Act, such actions do not affect wills, contracts, insurance or annuity policies which might have conditions concerning suicide. The text of Measure 16 is available as Appendix D in Battin, M.P., Rhodes, R. and Silvers, A. (eds.), *Physician-Assisted Suicide: Expanding the Debate*, above.

nents or that which might be made by proponents – would be an easy process, and it is difficult to predict what the longterm outcome might be. Yet given our history of escalatory moves by parties on both sides of the long and volatile debate, it is important to see what the next ante-upping moves might be – that is, how the dispute over physician-assisted suicide could get still worse, and what still further life might be fanned into this debate. Or perhaps some new move – perhaps an effort at cultural redefinition in the circumstances of terminal illness – might be seen not as escalatory but as conciliatory after all, and put an end to this debate with a resolution that would be more or less palatable to all, by allowing greater personal control in matters of bringing about one's own death without seeming to accept a physician's involvement in 'suicide'. This would be to some extent a smoke-and-mirrors solution, one of rhetorical rather than substantial change, but it might serve as a solution to our end-of-life dilemmas nevertheless.

LEGAL REGULATION

Engineering Rights

The Legal Status and Social Practice of Advance Directives

Cristiano Vezzoni

1. Introduction: Autonomy and Informed Consent

The relevance of the principle of autonomy is continuously increasing in western societies and in many fields an autonomous choice of an individual is seen as key to the acceptability of a relationship or a transaction. The situations for which the principle is considered relevant are several, from economic transactions to sexual relations. A direct translation of the principle in the area of health care is the doctrine of informed consent. This doctrine has slightly different consequences depending on the precise situation to which it applies. This paper focuses on the concept and practice of informed consent in medical practice and on its implication in the critical case of incompetent patients.¹

We examine first the relevance and diffusion of the doctrine of informed consent. In this connection we examine how the doctrine is implemented in legal rules, highlighting how this implementation can differ from declarations at the level of abstract principles. We then turn to the critical question whether it is possible to extend the principle of autonomy, specifically the right to give or refuse consent, to incompetent patients. If the answer to this question is yes, one possible means to implement the right is represented by advance directives. We survey therefore the legal status and social practice of advance directives in a large number of (mostly) western countries. Finally an attempt is made to identify the main important elements of a successful implementation in practice of the right to informed consent for incompetent patients.

The findings are the results of an international survey concerning the legal status and social practice of advance directives in several Western countries (18 countries, including more than 90 jurisdictions). Almost all western countries where some legal development concerning advance directives has taken place were included in the survey; a few countries where the situation is still rather underdeveloped (e.g. Italy, Japan) were included for purposes of contrast with the rest. For each country the relevant legal information was collected, mainly via internet or using legal literature on the subject.² On the other hand the available empirical literature mainly refers to USA and Canada.

1 This research project is funded by the Dutch Alzheimer Association (Alzheimer Stichting Nederland).

2 For this purpose, two books were particularly useful: Taupitz, J. (ed.) *Regulations of Civil Law to Safeguard the Autonomy of Patients at the End of Life. An International Documentation.*

2. Autonomy and Informed Consent in the Medical Sphere

Informed consent can be defined as the requirement that the patient consent to any invasive medical treatment. A necessary condition of the validity of the patient's consent is that he³ must be properly informed about his situation and the possible outcomes, and of the effects of proposed treatment. Generally, informed consent is seen as an absolute pre-condition of treatment: no treatment can be performed without the consent of the patient. In other words, doctors have no inherent prerogative to treat just because in their medical judgement treatment is indicated. Put negatively: a competent patient is entitled, for whatever reasons are important to him, to refuse any medical treatment, including treatment necessary to continued life (in recent years there has emerged widespread agreement that this right extends to refusal of artificial feeding and hydration).⁴

The elements explicit or implicit in the definition are as follows:

- **Subject:** a patient, whose autonomy is at stake.
- **Content:** permission to commit an otherwise prohibited invasion of bodily integrity.
- **Conditions of validity:** information about the medical situation and its possible outcomes (with or without various treatment) and awareness of the consequences of the performance of the proposed treatment.
- **Competence:** only a patient who can understand information given to him and make a competent decision can give valid consent.
- **Responsibility for securing consent:** the person who needs consent (usually the physician proposing the treatment) is responsible for securing the patient's consent, and therefore for ensuring that he is competent and adequately informed.

The first formulations of the doctrine of informed consent appeared quite recently, namely in the 50s, in decisions of US courts.⁵ The cultural background of this development was the individualistic values of American society, in the framework of an abiding suspicion of state power and changes in the relation between doctors and patients.⁶

Berlin and Heidelberg: Springer (2000); Sass, H.M., Veatch, R.M., Kimura, R. (eds.), *Advance Directives and Surrogate Decision Making in Health Care. United States, Germany, and Japan*. Baltimore and London: Johns Hopkins University Press (1998).

3 For ease of presentation we use the masculine form throughout to refer to both men and women.

4 See for example Meisel, A., 'Legal issues in decision making for incompetent patients', in Sass, H.M., Veatch, R.M., Kimura, R., 'Advance Directives and Surrogate Decision Making in Health Care. United States, Germany, and Japan', above, 187-208.

5 See Faden, R.R. and Beauchamp, T.L., *A History and Theory of Informed Consent*. New York and Oxford, Oxford University Press (1986), 235-273.

6 For US cultural background of informed consent, see Schuck, P.H., 'Rethinking Informed Consent', (2000) 103 *Yale Law Journal*, 899-959, [900-901].

Despite its recent appearance and particular cultural background, the doctrine quickly received international attention and in a relatively brief period achieved widespread acceptance. Nowadays, the informed consent of the patient is widely regarded as, under normal circumstances, a precondition of any medical treatment and the doctrine is accepted almost everywhere in western countries. Very few significant exceptions are allowed. In particular, the fact that a patient's withholding consent may shorten his life is not usually considered a sufficient ground for qualifying the right. In the survey carried out for this paper, Japan was the only country that does not accept these fundamental principles.

Despite such general support, however, implementation of the requirement of informed consent in specific legal rules is often problematic. For this reason it is possible to speak of a 'rhetoric of informed consent', whereby the doctrine is strongly asserted in abstract declarations contained in bills of rights and in medical ethical codes, while in fact its legal status is uncertain and compliance by the medical profession still more uncertain.

In the next part of this section we identify the main legal qualifications to which the doctrine can be subjected and we characterise the countries surveyed depending on the strength of their legal implementation of the doctrine of informed consent.

First of all, the doctrine of informed consent is generally qualified by the condition that the patient who expresses it must be competent and not subject by law to restrictive measures (e.g. mentally ill persons under guardianship). A minor who is competent at the time he gives or withholds consent is generally regarded as falling within the scope of the right. The most frequent solution is to identify a specific age (the lowest is 12, in the Netherlands) above which a minor patient is considered competent to express a legally binding consent or refusal.

Another important qualification of the principle concerns situations of emergency. In all the countries surveyed, if a person is in a condition threatening his life and temporarily incompetent to express consent, and no representative is available as a surrogate decision-maker, a doctor is expected to make treatment decisions in the person's best interests. This exception does not apply if the doctor knows of the patient's rejection of a particular form of treatment. The typical case of this is objection to blood transfusions for religious reasons.

Leaving aside these generally accepted qualifications, we can distinguish three groups as far as implementation in law of the requirement of informed consent is concerned:

- a first group, consisting of the Anglo-American countries (USA, England, Canada, Australia, New Zealand) together with the Netherlands and Denmark, exhibit a relatively unqualified commitment to the principle;
- a second group, including the other European countries (Germany, Switzerland, Austria, France, Norway, Sweden, Belgium, Italy, Spain, France) and

- Israel, accept the requirement in principle, although usually not in a formal legal sense, but impose more or less substantial qualifications;
- a third group, of which Japan is the only example in our survey, rejects the requirement of informed consent.

In countries of the *first group*, the doctrine of informed consent is explicitly recognised at common law and/or by statute. In the common-law countries, many judicial decisions affirm the almost absolute character of the requirement and its priority over the principle of the sanctity of life. The patient's granting or withholding of consent does not have to be grounded in rational considerations and no reasons have to be given to justify a particular choice. The right to refuse treatment is explicitly accepted even when death is the likely effect of the decision, including the situation in which this is the patient's reason for refusing consent. A doctor who performs treatment without consent is potentially liable both criminally and civilly.

The two continental European countries included in this group (the Netherlands and Denmark) have enacted statutes exhibiting a strong commitment to the autonomy of the patient, essentially the same as that in the common-law countries. In the Netherlands, for example, consent must in principle always be secured and the patient is presumed to be competent. In Denmark, particular attention is given to the information the patient receives prior to consenting, and if it is proved that the consent was given without enough information, the consent is not valid.

The countries belonging to the *second group* do recognize the requirement of informed consent, usually through official statements of national medical associations or in codes of medical ethics. In principle this recognition is more or less unqualified, but the legal status of the recognition is not entirely clear and in practice a more paternalistic approach seems to be widely accepted. The possibilities of legal enforcement are unclear.

Third group: Japan alone represents the legal situation where the requirement of informed consent is not officially recognised and medical practice is still rooted in a paternalistic approach. A dying patients is apparently rarely supplied with information concerning his condition and decisions are taken by the doctors and the family in the supposed best interests of the patient.

This brief classification suggests how varied is this translation of the right to informed consent into specific legal rules. If we were to go into more detail, many other problematic points would emerge. Analysing all of them would exceed the limits of this short paper. We focus on a specific problem: is it possible to respect the autonomy of an incompetent patient by extending to him the right to informed consent?

3. Autonomy for Incompetent Patients

Against the background of growing legal and medical acceptance of the doctrine of informed consent, the problem had to be faced of persons not capable of expressing consent at the time decision-making concerning treatment takes place.

Awareness of the problem can arise from reflection on the implications of the legal recognition of the principle of the autonomy of the patient. But there has been another important factor responsible for increasing attention to the principle of informed consent in the case of incompetent patients. This is the fact that in an increasing number of cases medical technology enables the doctors to keep patients who are no longer competent alive, imposing on them life-sustaining treatment they would not have wanted and that can add to their suffering and that of their families.⁷

These developments have called increasing attention to the following question: Is it possible to extend the principle of autonomy, specifically the right to give or refuse consent, to incompetent patients?

Answers to this question differ but, generally speaking, jurisdictions that accept the requirement of informed consent seem sooner or later to conclude that it would be wrong to deny a person the fundamental right to refuse treatment just because he is not capable of exercising the right at the critical time.⁸ A solution to the problem of current incapacity to give informed consent is the recognition of advance directives, by means of which the author himself decides in advance what treatments he consents to under specified conditions. Since the 1970s, advance directives have become accepted in many countries as a way in which a person who anticipates incapacity can exercise the right to informed consent.

4. The Definition of 'Advance Directives'

With the term 'advance directive' we refer very generally to *instructions a person gives in advance concerning health care*. The principal reason people do this is to ensure that their wishes concerning treatment be known to the responsible doctors in case they should later become incapable of making them known. In this most general definition we make no assumptions about who gives the instructions (e.g. age), how they are given (e.g. in writing), to what extent they have legal effect (e.g. binding the doctor), in what circumstances they are effective (e.g. terminal sickness), what the nature of the instruction is (e.g. refusal of a particular sort of treatment), and so forth.

7 Kutner, L., 'Due process of euthanasia: the living will, a proposal' (1969) 44 *Indiana Law Journal*, 539-554.

8 See Nys, H., 'Emerging legislation in Europe on the legal status of advance directives and medical decision-making with respect to an incompetent patient ("living wills")' (1997) *European Journal of Health Law*, 179-188.

In an advance directive the person making the directive (whom we will refer to throughout this article as the *author*) may himself specify the treatment he does or does not want under specified conditions. We refer to such advance directives as *treatment directives*. A treatment directive can be addressed directly to the responsible doctor, or indirectly via an appointed representative, or both. The author may also – either as an alternative to or in combination with a treatment directive – empower another person to express the author's wishes concerning treatment on his behalf. Such an advance directive we refer to as the appointment of a [health-care] representative. In some countries, such as the United States, the appointed health-care representative is referred to as having been given a 'durable power of attorney'.

A treatment directive can be either positive or negative. An example of a negative directive is the refusal of mechanical breathing support under specified conditions, such as a persistent vegetative state. In a positive directive the author requests specific life-prolonging treatment (such as resuscitation) or specific life-shortening treatment (such as euthanasia). However, if a given treatment is not medically indicated, it is doubtful that even a patient who is competent at the time could force a doctor's hand by insisting on it, and this applies *a fortiori* to a request made in advance. The legal significance of positive directives is therefore very limited in nearly all jurisdictions under consideration.⁹ For these reasons, the present paper is limited to negative treatment directives.

Finally the law recognising treatment directives can *require* a doctor to follow a valid one ('must' rules) or it can *allow* him to do so ('may' rules). In the latter case the legal recognition protects a doctor against possible civil or penal sanctions when the death of the patient is the result of following an advance directive.

5. The Legal Status of Advance Directives

If it is the autonomy of a competent patient on which the right to give or withhold informed consent rests, one might suppose that the same principle could be applied in case of consent or non-consent expressed in advance. In fact, consent is regularly asked of patients about to undergo an operation, regarding decisions the doctor may have to make while the patient is anaesthetised. At first glance, there would seem no reason why the same would not apply to expressions of consent – or withholding of consent – concerning a possible future condition, should the patient be non-competent at the time. But in fact the legal recognition of such a right is a relatively recent matter in all countries, and

9 The only country which explicitly gives legal status to positive treatment directives is the Netherlands; the law Termination of Life on Request recently adopted (April 2001), in which euthanasia is legalized under specific conditions and subject to a number of safeguards, permits euthanasia pursuant to an advance directive.

some still interpret the principle of informed consent in a restrictive or qualified way, as applicable – at least in full force – only to a competent patient with respect to a current situation.

In the following paragraphs, we give an overview of the legal status of advance directives in the countries surveyed. The main focus will be on the regulation of treatment directives. The appointment of a representative for health-care will be considered as an adjunct to the treatment directions a patient can give in advance.

For each country considered, the strength of the legal status of advance directives is assessed on the basis of the following elements:

- the existence of specific legislation or common-law rules recognizing treatment directives;
- the binding nature of the rules ('must' rather than 'may');
- the absence of substantial limitations on the right to give instructions in advance;
- the absence of substantial formal requirements;
- the possibility of appointing a representative for health-care decision-making.

To simplify the discussion, we have divided the countries surveyed into three groups, depending on the strength of the legal status of advance directives. The composition of the three groups is similar to that of the three groups identified above in connection with the recognition of the requirement of informed consent, but some adjustments are needed, as shown on Table 1.

Group 1 contains the Anglo-American countries (USA, England, Canada, Australia, New Zealand)¹⁰ plus the Netherlands, Denmark, Spain, Belgium and Israel. The countries in this group are characterised by a strong legal status of treatment directives, which are recognised by statute and/or at common law.

Group 2 includes the German-speaking countries (Germany, Austria, Switzerland), Norway and Sweden. In these countries some official steps (mainly by the national medical associations) have been taken in the direction of the recognition of treatment directives and debate on the subject is currently active. But the legal status of treatment directives remains uncertain and there is no clear indication that legislation will be enacted soon.

Group 3 includes France, Italy and Japan. These countries do not (explicitly) recognize the validity of treatment directives and public discussion of the subject is characterised by a high degree of vagueness.

¹⁰ For USA, Canada and Australia it is not always possible to give a uniform picture of the situation due to the differences between various jurisdictions (states, provinces or territory). Where important for the discussion, these differences will be mentioned.

Table 1: Acceptance of informed consent and legal status of advance directives by countries

		Acceptance of informed consent	Coverage of legal regulation	
			Treatment directives	Appointment of representative
GROUP 1: STRONG LEGAL STATUS				
	USA (1)	Strong	X	X
	Canada (2)	Strong	X	X
	Australia (2)	Strong	X	X
	New Zealand	Strong	X	X
	England	Strong	X	
	Netherlands	Strong	X	X
	Denmark	Strong	X	
	Spain (3)	Dubious	X	X
	Belgium (4)	Dubious	X	X
	Israel (4)	Dubious	X	X
GROUP 2: WEAK LEGAL STATUS				
	Germany	Dubious		X (analogy)
	Switzerland	Dubious		X (analogy)
	Austria	Dubious		
	Norway	Dubious		
	Sweden	Dubious		X (analogy)
GROUP 3: NO LEGAL STATUS				
	France	Dubious		
	Italy	Dubious		
	Japan	Absent		

- (1) In USA the situation varies among the states. Table 1 gives the most common situation. Despite the variability, the federal constitutional rights of the patient afford a quite homogenous framework in all states.
- (2) In Canada and Australia the situation differs slightly between the various jurisdictions. Table 1 therefore gives only a rough picture of the situation.
- (3) Even though no national legislation exists in Spain, the regional parliaments of Catalonia, Extremadura and Galicia enacted statutes fully recognizing advance directives; such legislation is considered here as representative for Spain situation.
- (4) In Belgium and Israel legislation on advance directives is pending. Table 1 assumes the bills now in Parliament will become law.

Group 1: Strong legal status

In all the countries belonging to this group, the legal status of treatment directives is strong. This means that the legal rules designed to protect the autonomy of the patient should he become incompetent are generally binding on doctors and the instruction in a valid treatment directive must be respected ('must' rules). The following description is based on the information reported on

Table

2.

Table 2: Source, legal force, limitations and formal requirements of advance directives in the group of countries with strong legal status (Group 1)

	Source	Legal force accorded	Limitations	Specific limitations				Formal requirements
				Specific treatment	Age	Condition of applicability	Pregnancy	
USA (1)	Statute + common law	Must rules	Extensive	artificial feeding and hydration	majority	terminal phase (sometimes)	x	Extensive
Canada (2)	Statute	Must rules	Medium		usually majority			Medium
Australia (2)	Statute + common law	Must rules	Extensive	palliative care	majority	terminal phase or current condition	x	Medium
New Zealand	Statute	Must rules	None					Minimal
England	Common law	Must rules	Medium	basic care	majority		x	Medium
Netherlands	Statute	Must rules	Mild		always over 16 or 12-16 if competent			Mild
Denmark	Statute	Must rules	Medium		majority	terminal illness		Mild
Spain (3)	Statute	Must rules	Medium	only treatment following good practice	majority			Medium
Belgium (4)	Statute	Must rules	Not defined					Not defined
Israel (4)	Statute	Must rules	Medium	only treatment prolonging the process of dying	majority	terminal illness		Mild

(1), (2), (3), (4) See previous Table 1.

The Anglo-American countries, members of a single common-law family, are easily located in this group. In most of these countries statutes also deal with treatment directives, but the common law gives a sufficient basis and may even supersede statutory limitations. In England, where the legal status of treatment directives is rather strong, there is no statute dealing with them and the Government has stated that it does not regard such a statute as desirable since the regulation at common law is sufficiently clear and has the advantage of flexibility.¹¹ The same situation can also be seen in some provinces and states in Canada and Australia respectively, and in a few states of the United States. Where statutes impose conditions, limitations or formal requirements, the courts in these countries often regard treatment directives not fulfilling these constraints as binding at common law.

As far as continental Europe is concerned, treatment directives have a particularly strong legal status in the Netherlands and Denmark. Given their strong commitment to the principle of autonomy of the patient, as seen in the previous section, the strong status of treatment directives in the Netherlands and Denmark could be expected.

Three countries which do not have a similar tradition of strong commitment to the doctrine of informed consent are poised to join group 1: Spain, Belgium and Israel. In Spain the regional parliaments of Catalonia, Extremadura and Galicia have enacted laws that explicitly provide for both treatment directives and appointment of a representative. This legal development has been welcomed elsewhere in Spain and similar developments in other regional parliaments are expected. In Israel, the courts have upheld the principle of patient autonomy in a number of cases to enforce treatment directives. As a result of a decision of the Israeli Supreme Court stressing the need for legislation to clarify the situation, a bill has been introduced in the Knesset; it was approved in March 2001 by a committee of the Knesset and is considered likely to be adopted in the near future. The bill enables anyone over the age of 18 and of sound mind to make a treatment directive refusing artificial support that would simply prolong the process of dying. In Belgium the pending bill to legalize euthanasia, introduced in December 2000 and considered likely to be enacted soon, provides for the recognition of advance directives, both in the form of treatment directives and of appointment of a representative. The possibility the bill affords of giving or withholding consent in advance is of considerable importance in the Belgian situation, since current law does not allow for delegation of the power to give informed consent and, in theory, no treatment can be performed on patients who have lost competence and cannot give consent, because no one else can decide on their behalf. In practice, of course, decision-making is based on the 'presumed will' of the patient or on informal consent given by a relative or friend.

11 See Lord Chancellor's Department, *Making Decisions – The Government's Proposals for Making Decisions on Behalf of Mentally Incapacitated Adults*, London, HMSO (1999).

With the sole exception of England and Denmark, all the countries belonging to this group have also recognised the appointment of a representative for health-care decision-making, often in the same statute recognising treatment directives. In these countries the coverage of legal regulation is therefore complete. The powers of the appointed representative are generally as extensive as those of a competent patient, but his decisions are constrained if there is also a treatment directive.

In the countries of Group 1, a valid treatment directive must be respected (see Table 1, column 2: legal force accorded to advance directives). There is no exception to this rule.

The conditions of validity differ in minor ways among the various jurisdictions. In general, only a competent patient, adequately informed and free from undue pressure can make a valid advance directive. Concerning the age of the author, statutes providing for advance directives are sometimes more restrictive than for informed consent. Generally the author must have reached the age of majority. The doctrine of 'competent minor' holds only in New Zealand, in one province of Canada (Manitoba) and in the Netherlands. In the Netherlands, the low age limitation for informed consent apparently also holds in the case of a treatment directive: patients 12 years or older are presumed competent to make medical decisions.¹²

The degree to which a patient can express instructions in a treatment directive can be affected by a variety of limitations (see Table 2). A typical case of such limitations is represented by various states in the USA, where the three most common limitations provided for in statutes concern the medical state of the patient (a directive is only effective in the case of terminal illness or a permanent unconscious state), the treatment that can be refused (artificial nutrition and hydration sometimes being excluded or limited), and pregnancy. Despite sometimes rather restrictive legislation, however, non-statutory advance directives are usually considered by American courts to be a valid expression of the wishes of the patient and therefore binding on doctors. Moreover, the validity conditions specified in a statute can be overruled by the constitutional 'right of privacy'. Thus references to terminal illness or permanent unconsciousness are not necessarily considered by the courts as exhausting the conditions under which an advance directive can be valid. Similarly, restrictions on the treatment that can be refused are constitutionally dubious. Finally, the exclusion of pregnant women has been held unconstitutional, at least before the foetus is viable.¹³

The technical explanation for the approach of the common law courts is that legislation does not create a new right, because the principle of autonomy and the requirement of informed consent are based on common law and on the right of privacy contained in the Federal and some state constitutions. A case similar to the USA is represented by Australia, where the legislation in the

¹² However, the age of majority is required to make a valid appointment of a representative.

¹³ See Meisel, A., 'Legal issues in decision making for incompetent patients', above.

jurisdictions that have enacted statutes on treatment directives includes quite extensive limitations, but the appeal to common law serves to weaken the statutory limitations. In effect, once the right to consent to or refuse medical treatment in advance is recognised, it seems to be difficult for common-law legal systems to subject this right to limitations that do not apply to a competent patient in a current situation.

In some other countries belonging to this group there are potentially serious limitations on patient autonomy. For example in Spain, the only instructions binding on doctors are those which conform to good medical practice. Clearly, if taken at face value, such a provision significantly weakens the force of the right to refuse medical treatment in advance. Another substantial limitation is contemplated in the pending Israeli bill: a treatment directive is binding only if the patient is in a terminal condition and the treatment would simply prolong the process of dying. Such a condition can also be observed, albeit in a more limited form, in Denmark: if the patient is terminally ill, a doctor is obliged to comply with a treatment directive; on the other hand, if the patient's condition is one of serious impairment causing grave invalidity,¹⁴ a treatment directive guides but does not bind a doctor.

At the opposite end of the spectrum are New Zealand and the Netherlands, where there are no limitations on the validity of a treatment directive, except the general requirement of competence of the author. In these countries the right to express instructions in advance is extensive and unconstrained.

As far as formal requirements are concerned (see Table 2, last column), the differences among jurisdictions run parallel to the situation concerning limitations: on the one hand is the USA, where state statutes often impose extensive formal requirements;¹⁵ on the other hand is New Zealand, where no formal requirements are specified. However, there seems to be a common denominator underlying the differences: some documentation of a treatment directive (not necessarily writing) and at least one witness is generally required. A requirement of periodic renewal is usually not imposed (except in Israel: renewal every five years), but it is a common opinion that a more recent directive carries more weight, and in case of doubt this could be decisive.

14 E.g. dementia; more examples are described in guidelines issued by the National Health Care Directorate. See Hybel, U. 'Country Report Denmark', in Taupitz, J., *'Regulations of Civil Law to Safeguard the Autonomy of Patients at the End of Life. An International Documentation'*, above, 491-528.

15 As an example of a set of requirements, we can refer to the West Virginia Living Will Law (1994): "A living will (...) shall be : in writing; executed by the declarant or by another person in the declarant's presence at the declarant's express direction if the declarant is physically unable to do so; dated; signed in the presence of two or more witnesses at least eighteen years of age; and signed and attested by such witnesses". This is followed by the conditions for being a valid witness. Reported in Zucker, M.B., *The Right to Die Debate*, Westport and London, Greenwood Press (1999) 77.

Group 2: Weak legal status

This group is characterised by a rather uncertain and weak legal status of advance directives. Nonetheless, discussion of the issue is active and some steps toward legal recognition have been taken. Appointment of a representative for health-care decision-making is legally recognised in three of the five countries: in Germany by a specific law, in Switzerland and Sweden by analogy with the appointment of a representative for financial matters.¹⁶

More complex is the situation concerning treatment directives. The main point of discussion concerns the binding nature of these directives. The usual position, held especially by the medical associations, is that a treatment directive gives relevant information on which a doctor can determine the presumed will of an incompetent patient, but in itself is insufficient to bind a doctor's hands. A certain degree of freedom remains, within which a doctor can decide whether the instructions given in advance by a patient should be followed or not. It is clearly accepted, on the other hand, that a doctor may legally carry out a treatment directive ('may' rule).

One argument against giving treatment directives binding legal force is that they are necessarily expressed in such general terms that they can hardly be decisive in a concrete situation. This can indeed be a serious problem in the implementation of treatment directives (see below, section 6.3). However, it does not seem to afford a sufficient reason for a categorical rejection of their binding force when they are clearly applicable. And considerable improvement in the working of treatment directives can be obtained by coupling them with appointment of a representative. Moreover there are many situations in routine medical practice where a similar problem is latent but in practice the objection to patient autonomy is not made. For example, as we have already noted, in the case of major surgery requiring total anaesthesia it is common practice, based on the requirement of informed consent, to seek the consent of the patient in advance to additional surgery that may prove necessary once the operation has begun.¹⁷

The role played by the arguments against binding force differs among the countries belonging to this group. On one hand we have Germany, Sweden and Norway, where the arguments are seen as insurmountable objections to giving treatment directives binding force and the medical associations and/or the governments have officially declared that such a legal development would be undesirable. On the other hand, Switzerland and Austria seem to exhibit a more

¹⁶ Despite this official recognition, in Sweden the legal status of an appointed representative is weak and the binding force of his decision is far from certain. See Westerhall, L., 'Country Report Sweden.' In Taupitz, J., *Regulations of Civil Law to Safeguard the Autonomy of Patients at the End of Life. An International Documentation*, above, 877-949.

¹⁷ Another argument used to deny binding force to treatment directives is based on the idea that the current will of the patient may not be reflected in a treatment directive made (long) in advance. See Nys (1997), *Emerging legislation in Europe on the legal status of advance directives and medical decision-making with respect to an incompetent patient ("living wills")* above.

pragmatic approach and some legislative change to give treatment directives binding force appears more likely.

Something more should be said about Germany, where the literature takes the position that treatment directives should only be treated as binding in two cases: that of a terminal patient who, for example upon admission to hospital, provides that should he become incompetent, he refuses long-prolonging treatment, and that of a directive made by a healthy person that, should he be in a persistent vegetative state, he refuses life-prolonging treatment. A treatment directive refusing treatment if the author becomes incompetent due to a disease such as Alzheimers would apparently not be considered binding, because German law emphasises the welfare and current will of the patient above prior written expressions of the patient's will. However this may be, given the weak legal status of advance directives, the meaning of limitations on what a patient can request in advance is unclear. This is the crucial point of difference with the countries of Group 1, where similar limitations draw the line between binding and non-binding treatment directives.

Group 3: No legal status

The countries belonging to this group do not legally recognise either treatment directives or the appointment of a representative. Together with two European countries, we find Japan in this group. The strong opposition of the medical profession may help explain the legal situation in these countries. However the situation is not uniform in the group. Japan does not recognise the principle of informed consent at all, while France and Italy do so at least in theory, and in both countries bills have been introduced in the legislature, but the chances of enactment are rather low (France) or non-existent (Italy). But theoretical recognition of the requirement of informed consent stands in these countries in the framework of a paternalistic medical profession.

6. The Social Practice of Advance Directives

The legal recognition of advance directives does not by itself assure the achievement of the principle of autonomy for incompetent patients; many other problems remain to be solved in the actual social practice of advance directives. By 'the social practice of advance directives' we refer to the whole chain of social behaviour beginning with availability of information and facilities to potential users and covering the process of actually making an advance directive, of making it available to doctors, and finally, the actual implementation of advance directives.

Unfortunately very few empirical studies have been made on the social practice of advance directives, and what there has been mostly concerns the USA and Canada and deals only with particular aspects of the problem. In short, no systematic results are available, but the sparse empirical literature on the subject suggests that legal constraints, the attitudes and professional ethics

of doctors, the practical circumstances surrounding the making of advance directives and their availability to doctors, and finally the nature of the decision-making concerning treatment of a non-competent, dying patient, combine so as largely to frustrate the objectives that advance directives are supposed to serve.

Due to the scarcity of empirical evidence, this paragraph is limited to listing the phases involved in the social practice of advance directives (see Box 1). For each phase, we will then offer a more detailed analysis, bringing empirical information to bear where possible.

Box 1: Schematic overview of the social practice of advance directives

DEMAND

- *Demographic demand*: the share of elderly people in population and prevalence of diseases such as senile dementia, HIV/AIDS
- *Social demand (potential and actual)*: the level of acceptance and concrete interest in ADs among the population as a whole and among specific categories and, in particular, the elderly
- *Diffusion*: the frequency of ADs in the population and the proportion of people with an AD in the most important categories, e.g. elderly population and (potentially) incompetent persons

INFORMATION (legal and practical) available to potential users and others

- *The existence of active and passive suppliers of information* (e.g. physicians, organisations such as the NVVE, the government, the media, health care organisations providing programs such as Advance Care Planning)
- *The availability of information*
- *The actual level of legal and practical knowledge* for the subject involved

PREPARATION

- *Assistance*: discussion with family, doctors (how do doctors respond to inquiries), lawyers and organisations
- *Timing*: when is an AD considered? when is it completed?
- *Contents*: conditions, treatments, representative

LATENCY

- *Archiving*: where do people register, deposit or otherwise make known their ADs?
- *Validity through time*: do people renew their ADs? how often? Do they change their wishes?

IMPLEMENTATION

- *Legal knowledge* among health care professionals concerning the legal status of ADs; sources of legal information
- *Factual knowledge* of the existence of an AD and of the existence of specific conditions
- *Acceptance*: do the family, the doctors, etc. accept the contents of treatment directives and the appointment and decisions of a proxy decision-maker?
- *Effects on treatment*, assuming that the content of the AD differs from otherwise accepted medical practice

ENFORCEMENT

- *Legal and extra-legal measures* (ex-ante and ex-post) available in theory and actually taken to secure conformity with ADs and their effectiveness (special and general effects)

6.1. Demand for advance directives

6.1.1. Demographic demand

The most important source of potential demand for advance directives is represented by the elderly, particularly those afflicted by diseases such as senile dementia. Other potential users (e.g. persons about to undergo a serious operation) certainly exist, but their numbers are relatively small and there seems no reason to anticipate a significant increase.¹⁸ The most important demographic factor influencing the level of potential demand is therefore the size of the elderly population and, in particular, of those in it suffering from or expecting to suffer from senile dementia. Available demographic and medical information indicates that this population is large, increasing, and expected to continue to increase in the foreseeable future. The few data available suggest the probable magnitude of the phenomena involved. A very large number of predominantly elderly people suffer from Alzheimers Disease, by far the most common cause of dementia. The population afflicted with Alzheimers is presently estimated at 130,000 in the Netherlands (5% of those over 65; 20% of those over 80). Because of the ageing of the population, the numbers of demented persons and their proportion of the population will rise in the near future – one estimate is that in the absence of a medical breakthrough, about three times as many Americans will suffer from Alzheimers in 2040 as in 2000.¹⁹ The frequency of death due to stopping or not initiating life-prolonging treatment in populations where the rate of Alzheimers is high gives another indication of the magnitude of potential demand. Eight percent of all deaths in the Netherlands, and 23% of all deaths in nursing homes – many of which involve persons suffering from Alzheimers Disease – follow upon a decision not to administer artificial feeding and hydration to a patient who spontaneously stops eating and drinking (at

18 In all cases in which the progress of a disease can be expected to lead to a final reduction of the sufferer's competence, an advance directive can be of use to try to maintain autonomous control over the decision-making process. In the last phases of cancer, for example, a patient may experience a state of confusion or complete inability to make competent decisions; the same can be true for persons suffering from AIDS. [Note the considerable literature on decision-making at the end of life of patient with HIV/AIDSs: see for instance Wegener, N.S., et al., 'End-of life discussions and preferences among persons with HIV' (2001) *JAMA* 285, 2880-2887; Ho, V.W.K., et al., 'The effect of advance care planning on completion of advance directives and patient satisfaction in people with HIV/AIDS' (2000) *AIDS Care* 12, 97-108; Kohut, N., et al., 'Treatment preferences of people with human immunodeficiency virus: implication for advance directives' (1997) *Journal of Clinical Ethics* 8, 124-135. Finally, persons concerned about the risk of suffering from a persistent vegetative state may be interested in the possibilities afforded by advance directives: see for instance Teno, J.M., and Lynn, J., 'Putting advance-care planning into action' (1996) *Journal of Clinical Ethics* 7, 205-213; Miller, R.G., et al., 'Practice parameter: the care of the patient with amyotrophic lateral sclerosis (an evidence based review)' (1999) *Neurology* 52, 1311-1323.

19 See Kawas, C.H. and Brookmeyer, R., 'Aging and the public health effects of dementia (Editorial)' (2001) *New England Journal of Medicine* 344, 1160-1161; Office of Technology Assessment, U.S. Congress (OTA) *Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Others Dementias*. (1987) and *Confused Minds, Burdened Families: Finding Help for People with Alzheimer's and Other Dementias* (1990) Washington DC: U.S. Government Printing Office.

present, of course, there probably is no advance directive in most of these cases).²⁰

6.1.2. Social demand

With the expression ‘social demand’ we refer to the level of acceptance of and concrete interest in advance directives among the population as a whole and among specific categories, in particular the elderly. Very little information is available on this, but the results of public opinion research in various European countries gives some indication. On the whole,²¹ there seems to be very strong social support for the principle of patient autonomy and in particular for the right of a person to specify in advance which medical treatments he does not want to undergo should he become non-competent.²²

Public support for advance directives is probably connected with growing awareness of the emotional and physical suffering associated with senile dementia, particularly when, in its later stages, it involves confinement in a psycho-geriatric institution. Anticipation of such a fate is a common reason given in public discourse for the choice to forego life-prolonging treatment (or, in the Netherlands, to request euthanasia²³). The low public regard for the quality of life demented people can expect in medical institutions finds support in the medical literature. For example a study conducted in a large hospital in New York shows that, despite a poor prognosis (6-month mortality higher than 50%), elderly people afflicted by end-stage senile dementia and hospitalised for severe pneumonia or a hip fracture rarely receive adequate pain relief; they

20 See Griffiths, J., Bood, A., and Weyers, H., *Euthanasia and Law in The Netherlands*, Amsterdam, Amsterdam University Press (1998), 216, note 49. More generally between 1990 and 1995 there was a striking increase in the frequency in nursing homes of abstinence with the express purpose of hastening the death of the patient. *Ibid.* 45.

21 There are some exceptions. For example, in two otherwise very different countries, Italy and Japan, similar family structure and culture may stand in the way of social acceptance of advance directives. Care of a dying person is a family matter and decisions are taken by the family, not the patient. Even the suggestion of withholding or withdrawing treatment is often regarded (by individual family members or, in their perception, by others) as an indication of insufficient solidarity with the dying family member. See Kimura, R., ‘*Death, Dying, and Advance Directives in Japan. Sociocultural and Legal Points of View*’, above, 187-208; Cencioni, R., and Del Grosso, M., ‘*Consenso informato e direttive anticipate: i risultati di uno studio pilota condotto sui medici-chirurghi della provincia di Cremona*’ (2000) (unpublished paper).

22 Survey in France, published in the site of the Right to Dye Association (<http://perso.club-internet.fr/admd/fenetre.htm>); Trappenburg, M. and Holsteyn, J., ‘Citizens’ opinions on new forms of euthanasia. A report from the Netherlands’ (2001) 35, *Patient Education and Counselling*, 63-73. The high level of public support also applies, albeit to a lesser extent, to euthanasia – for which there is, of course, far less widespread political support. The idea of patient autonomy seems, among ordinary people, in some way to override the ideological differences typical of modern society.

23 The current Dutch Minister of Health has repeatedly argued for the right to request euthanasia in an advance directive – a right incorporated in the recently enacted law that gives legislative recognition to the legalisation of euthanasia in the Netherlands – on precisely these grounds.

there was also no evidence that medical decision-making took care to minimize burdensome interventions.²⁴

6.1.3. Diffusion of advance directives

Except for one English study, all our empirical information concerning the actual use of advance directives comes from the USA and Canada. The settings where the studies were conducted are varied and the samples are rarely representative. It seems that in Canada and in the USA the use of advance directives is not rare, especially where informational intervention occurs.²⁵ Institutional settings such as nursing homes or residential houses and hospitals seem to favour the frequency of advance directive.²⁶ However, where the samples were more representative of the population, the frequency of treatment refusal in advance (the study was not limited to formal advance directives) is lower than in the other studies.²⁷

The only European study, conducted in Great Britain, presents an even poorer situation: in a sample of 74 elderly people, not a single advance directive was found and only 4 people knew what an advance directive is.²⁸

The reasons for this low level of demand is one of the subjects that must be clarified in connection with the social practice of advance directives. Two explanation suggest themselves: first, a genuine indifference to the tool itself; second, a lack of legal and practical information reaching potential users about how they could use the tool to preserve their autonomy should they become incompetent.

As we will see in the next section, some empirical results seems to support the second explanation.

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- 24 Morrison R.S., and Siu A.L., 'Survival in End-Stage Dementia Following Acute Illness' (2000) 284, *JAMA*, 47-52.
 - 25 Molloy, et al., 'Systematic Implementation of an Advance Directive Program in Nursing Homes. A Randomized Controlled Trial.' (2000) 283, *JAMA*, 1437-1444; Ho, et al., 'The effect of advance care planning on completion of advance directives and patient satisfaction in people with HIV/AIDS', above.
 - 26 Molloy, et al., 'Systematic Implementation of an Advance Directive Program in Nursing Homes. A Randomized Controlled Trial.', above; Guru, V., et al. 'Response of Paramedics to Terminally Ill Patients with Cardiac Arrest: an Ethical Dilemma' (1999) *Canadian Medical Association Journal* 161, 1251-1254; Morrison and Siu, 'Survival in End-Stage Dementia Following Acute Illness', above; Dendaas, N., et al., 'Responding to SUPPORT: an academic medical center examines its end-of-life care practices' (2001) 21, *Journal of Pain and Symptom Management*, 121-128.
 - 27 Liao, et al., 'Quality of last year of life of older adults: 1986 vs. 1993' (2000), 283, *Jama*, 512-518. The study refers to the situation in 1993, so the reliability of this result is nowadays uncertain.
 - 28 Emanuel, L., et al., 'Views of elderly people on living wills: interview study' (2000) 320, *BMJ*, 1640-1641.

6.2. Information

How people acquire legal knowledge is in general very poorly understood, and this is certainly the case for knowledge of advance directives. Probably a person's immediate social surroundings (family, friends, neighbours, colleagues, etc.), his general practitioner, the organizations of which he is a member, consumer and patient associations, and the general media are the most important sources. Especially in the United States, media attention to cases in which a prominent person makes use of advance directives, or in which such a person dies an undignified death due to the absence of one, probably convey basic information to a large public.²⁹

The systematic implementation of information programs for potential users of advance directives seems to be an effective way of getting legal information to potential users.³⁰ Some such programs have shown interesting results. For instance, a pair-matched study conducted in Canada in six nursing homes³¹ shows that the systematic supply of information on advance directives dramatically increases both the rate of use (70% in the nursing homes where the information program was carried out as against 57% in the matched nursing homes), as well as the quality of treatment directives. The vast majority of those who after participation completed an advance directive gave detailed instructions taking into account different situations and a number of possible treatments. By contrast, in the nursing homes where no specific information was given, more than two thirds of the directives simply requested 'no resuscitation'. Similar results were found in another Canadian study, of HIV/AIDS patients in Toronto. The systematic supply of information in the context of 'advance care planning' increased the completion rate of advance directives from 16 to 41% in the space of six months.³²

The availability of information about advance directives seems then to be a key variable as far as actual social practice is concerned. In general, in most countries, the level of legal knowledge about patient autonomy, and in particular advance directives, is probably very low, although there is no solid empirical information available on the subject. In practice, most people (patients and their families) simply accept their doctors' decisions.

Right-to-die associations fulfil a probably important role in spreading information; but despite their aim of reaching a large number of people, their activity is probably rather marginal in most countries, reaching primarily a fairly small group of persons already aware of their rights.

29 For instance, see the reaction after the death of Jacqueline Kennedy, Nixon; see also about the congressman Morris K. Udall the editorials of Udall, D., 'When someone is alive, but not living' (1999) 133, *Newsweek*, 24, 12

30 For example, the Uniform Rights of the Terminally Ill Act, 1989, in the United States.

31 See Molloy, W., *et al.*, 'Systematic Implementation of an Advance Directive Program in Nursing Homes. A Randomized Controlled Trial', above.

32 Ho, *et al.*, 'The effect of advance care planning on completion of advance directives and patient satisfaction in people with HIV/AIDS', above.

In countries where advance directives have a strong legal status, the institutional information supplied by hospitals and consumer associations and the systematic implementation of information programs for the potential users of advance directives (e.g. the Patient Self-Determination Act, 1989, in the United States) are probably more effective ways of getting legal information to potential users.

6.3. Preparation

The phase of preparation starts at the moment a person decides to make an advance directive. It is an obvious but not a trivial truth that the will to make an advance directive is not sufficient to produce a valid and effective one. In fact, it seems that despite an increase in the rate of completion of advance directives after specific informational programs, the quality of directives remains low and not consistent with legislation.³³ It has also been observed that the clarity of the medical instructions in advance directives is often so low that they cannot effectively contribute to medical decision-making.³⁴

Problems of legal validity can largely be dealt with in fairly simple ways, such as the dissemination of standard forms that match the legal requirements. In fact, where advance directives are legally recognised, standard forms usually exist.³⁵ The problem with these standardised examples is that they rarely can reach the level of specificity required if an advance directive is to be effective when the author becomes incompetent. They are often generic, not going much further than a simple declaration of values. Incidental evidence suggests that the role of legal advisors in drafting advance directives can sometimes be important, but how often they are involved and under what circumstances – and how much difference their involvement makes to the quality and effectiveness of an advance directive – is uncharted territory.

The medical quality of advance directives is a more difficult problem. It is widely supposed that this is directly affected by the relationship between doctor and patient (how long-term and encompassing it has been) and their communication concerning the patient's future treatment wishes (how openly, extensively and repeatedly they discuss the matter).³⁶ Several efforts to improve

33 Even after a specific information program on advance directives, a quarter of them was found to be invalid under Ontario law, *Ibid.*

34 Teno, *et al.*, 'Putting advance-care planning into action', above.

35 A national standard form often accompanies the statutes legalising advance directives. Alternatively, in almost all countries right-to-die associations are active in distributing forms for the completion of an advance directive.

36 See Wenger, N.S., *et al.* 'End-of life discussions and preferences among persons with HIV' (2001) 285, *JAMA*, 2880-2887; Teno and Lynn, 'Putting advance-care planning into action', above.

the medical quality of advance directives in order to render them more effective at the time of implementation seem to have had some effect.³⁷

Relevant in connection with the communication between doctor and patient is the question of timing. Ideally, the instructions in an advance directive should be formulated neither too late nor too early: long enough before the point of implementation that the communication can take place in an unhurried way, but not so long before that the directive deals with an abstract, unknowable situation. There seems to be no information available on this matter, nor about the related question, how frequently and under what circumstances advance directives are renewed (especially when regular renewal is not a legal requirement). The aspect of timing is particularly important for patients diagnosed with some form of deteriorating dementia. Such patients can expect to be fully competent to complete an advance directive for only a limited period. Postponement involves the risk of being overtaken by incompetence. It has been suggested that if there is no initiative from the patient or his family, the doctor himself should raise the possibility that the patient might want to express his wishes or instructions in advance of the period when he has become incompetent.³⁸ But it is not known to what extent doctors actually do this.

6.4. Latency

The effectiveness of an advance directive is obviously dependent on its availability at the moment the doctor or the family must make medical decisions for the incompetent author. It is therefore essential that the relevant actors be informed in advance about its existence. This is not always easy to accomplish, above all in the case of emergency treatment by medical staff who do not know the patient. In this regard, in an ethical discussion reported in *Medical Economics* (October 1999), one of the participants said:

‘...typically, by the time somebody says, “I think the patient has a DNR order,” the EMS (emergency staff) people have already started to intubate her. The patient ends up in the emergency room, and somebody says, “I have documentation that this patient was supposed to be DNR.” Now what do we do?’³⁹

But the problem of the availability of an advance directive does not end with emergency cases. For instance, one study found major difficulties in the trans-

37 For example the “Let Me Decide” advance directives developed in the framework of a complete educational program by William Molloy at McMaster University, Ontario, Canada (www.newgrangepress.com/LMD.html). See Molloy, *et al.*, ‘Systematic Implementation of an Advance Directive Program in Nursing Homes. A Randomized Controlled Trial’, above.

38 Riesemberg, D., ‘Hospital Care of Patients with Dementia’ (2000) 284, *JAMA*, 87-89

39 Gaylin, W., *et al.*, ‘Who really has the last word on a DNR?’ (1999), *Medical Economics* October 11, 116-126

mission of advance directives to hospitals at the time of admission of nursing home residents.⁴⁰ In the Netherlands, where the organizations that distribute large numbers of standard-form advance directives urge those who use them to discuss their advance directive with their family doctor and have a copy on file with him, it is not known how many authors of advance directives actually do this.

The Danish Health Care Ministry has tried to overcome the problem of availability by instituting a Living Will Data Bank (*Livstestamentregistret*). Registration of advance directives is supposed to improve their availability to doctors. To achieve this end the law requires that doctors consult the register when considering life-prolonging treatment for an incompetent patient. In practice, however, this provision is apparently ignored.⁴¹

6.5. Implementation

The problem of implementation of an advance directive refers mainly to the question whether advance directives affect the behaviour of health-care suppliers. Despite the critical importance of the question of implementation, very little empirical information is available. What there is gives contrasting results. Some studies seem to suggest that at present, even in countries where advance directives have legal force, the answer to this question is rather negative.⁴² The documents usually being quite generic, doctors can often claim that the patient's situation does not fall under the specification of his advance directive. For instance, an empirical study on elderly demented patients with pneumonia or hip fractures shows that there is no evidence of an effect on treatment due to the existence of an advance directive.⁴³ Such findings tend to support the position of many sceptics, that it is impossible to define one's wishes prospectively. On the other hand, a study conducted in Canada found a significant effect of reduction of hospitalisation for nursing home residents with advance directives compared to others without advance directives.⁴⁴

40 Danis, M., et al., 'A prospective study of advance directives for life-sustaining care' (1991), 324, *New England Journal of Medicine*, 882-888.

41 Vestergaard, J., 'Danish law concerning medical aid in dying' (1999) Paper presented at the Conference on Living Wills, Consulta di Bioetica, Milan, November 1999.

42 Teno, J.M. and Lynn, J., 'Putting advance-care planning into action', above.

43 Morrison and Siu, 'Survival in End-Stage Dementia Following Acute Illness', above.

44 Molloy, 'Systematic Implementation of an Advance Directive Program in Nursing Homes. A Randomized Controlled Trial' above. On the effects of advance directives on treatment see also SUPPORT Principal Investigators 'A controlled trial to improve care for seriously ill hospitalized patients.' (1995) 274, *JAMA*, 1591-1598; Teno, J.M., et al., 'Do advance directives provide instructions that direct care?' (1997), 45, *Journal of the American Geriatrics Society*, 508-512.

6.6. Enforcement

It is impossible to say anything very specific on the subject of enforcement of the legal rules surrounding advance directives. In principle, where advance directives are recognized the full range of civil, criminal and disciplinary remedies is available, both to enforce the patient's right to refuse treatment in an advance directive and to enforce a doctor's duty to treat in the absence of a valid advance directive (which of course includes enforcement of whatever legal limitations there may be).

As reflected in sporadic case law in many jurisdictions,⁴⁵ enforcement can be either *ex ante* (prospective) or *ex post* (after the fact). *Ex ante* enforcement makes use of civil actions to force a doctor to treat or not to treat (declaration of rights; injunction or equivalent actions). *Ex post* enforcement is in practice mostly through criminal proceedings, usually for improperly having let a patient die in violation of a duty to treat; in theory a doctor could also be criminally prosecuted for having treated without consent. Disciplinary action could also be taken in both situations, although we are not aware of such cases.⁴⁶ Finally, civil damages (in particular, in tort⁴⁷) are in theory available both for wrongfully having kept a patient alive and for wrongfully having let him die; it has also been suggested that treatment in violation of the requirement of informed consent may relieve the patient (or his insurer) of the duty to pay for the further and hospitalization medical costs thereby occasioned.⁴⁸

7. Engineering Rights

The policy goals of advance directives are ambitious. But it is far from clear that legal recognition of advance directives, however strong it may be in theory, actually secures realisation of the goals of promoting patient autonomy and preventing over-treatment and its associated costs. The social practices that surround making and implementing advance directives may largely frustrate realisation of legislative goals and patient wishes.

The central focus of this last section is on the question what the conditions would be under which advance directives could answer the increasing social demand for respect for the autonomy of incompetent patients. It is in this con-

45 Some of the case law is only relevant by analogy: for example, the civil cases in many jurisdictions brought by relatives of a person in irreversible coma to force the doctor to cease treatment, which generally involve surrogate decision-making in the absence of an advance directive. See for example the Stinissen case, in Griffiths, J., Bood, A. and Weyers, H., 'Euthanasia and Law in The Netherlands', above, 77-78.

46 See for a comparable situation the case of Mia Versluis, *Ibid*, 47-48.

47 In some countries, such as the Netherlands, the doctor-patient relationship may be conceived primarily in contractual terms, which may have legal-technical consequences for civil enforcement.

48 See Griffiths, J., Bood, A. and Weyers, H., 'Euthanasia and Law in The Netherlands' above, 263.

text that we use the expression ‘engineering rights’, suggesting that the simple affirmation of a right, even if in legal terms and in legislation is not enough to be sure that it is actually used and respected. If not embedded in broader changes in the cultural and social framework, advance directives may often have little chance of success. This idea could be used by sceptics to argue that it is not desirable to introduce legally binding advance directives until the other conditions have been achieved (e.g. changes in the doctor-patient relationship). However the attempt here is to show that less ambitious changes in the social practice of advance directives could be effective and help to redefine the dynamics between health-care suppliers and users. ‘Engineering’ is thus not used as a synonym for ‘imposing’⁴⁹ but in the sense of creating the most favourable conditions for the success of advance directives, in order to guarantee as much as possible that the autonomy of incompetent patients is respected.

7.1. Legal recognition of advance directives

From the findings of the survey, it seems that a first condition for the effectiveness of advance directives is a clear legal status. When advance directives are not legally recognised, their effect on social practice is necessarily happenstance: patients cannot rely on them to have a real impact on treatment should they become incompetent and most people will not bother to make an advance directive; a doctor can simply disregard an advance directive, regarding it as non-binding and not relevant. Once their legal validity is recognised, advance directives will generally be considered to bind treatment decisions: disregarding them becomes difficult and patients will have more confidence that they can affect the decision-making process, should they become incompetent. The higher diffusion of advance directives in the countries that recognise them seems to support this idea.

This does not mean that the goal of a secure legal status need always be achieved through legislation. Especially in the Anglo-American countries, as we have seen, the common law already affords a strong legal status to advance directives.

However, in continental Europe the two countries where advance directives have a strong legal status (the Netherlands and Denmark) have recognised them through specific legislation. This seems to be the path non-common law countries will follow in affording advance directives a strong legal status and dealing with their shortcomings.

Of course, the significance of legal recognition depends on an effective system of enforcement, that significantly increases the chance that a valid advance directive is followed by a doctor and, if this does not happen, gives the

⁴⁹ On the negative effects of ‘engineering’ in the sense of imposing a predetermined solution that does not take account of actual conditions and constraints, see Scott, J.C., *Seeing Like a State*, New Haven and London, Yale University Press (1998).

patient and his family *ex-ante* and *ex-post* possibilities to vindicate the right. Experience in Israel and elsewhere seems to suggest that prospective enforcement through judicial orders is inefficient, prolongs the decision-making process and undermines the responsibility of medical staff, so reliance will have to be largely on the threat of legal and/or professional sanctions for non-compliance.

Finally, it is important that advance directives be accompanied by legal recognition of the power to appoint a representative for health-care decision-making whose withholding of consent must be respected. The combination of tools strengthens the force of advance directives and, as seen above, deals with arguments against advance directives based on the supposed impossibility of knowing the future and what one would want to choose.

One could argue that only legal provision for the appointment of a representative is needed. But a treatment directive does represent a means for the patient to constrain in advance his representative's choices concerning his health. Moreover, a patient may choose not to burden his loved ones with such decisions as much as he can decide himself about his future.

To summarize, a vital social practice in which patients realise their autonomy by means of advance directives requires as a first condition that advance directives have a strong legal status and that people can choose the most appropriate way (treatment directives and/or appointment of a representative) of implementing their autonomy, with reasonable assurance that their wishes will be respected.

7.2. Improving the practice of advance directives

Full legal recognition of advance directives is not in itself sufficient to assure a social practice that respects the autonomy of the incompetent patient. More is needed to improve their diffusion, use and implementation in practice.

The quality of the documents should increase, containing as much information as possible in a clear and unambiguous form, so that legitimate problems of interpretation will decrease. One obvious target consists in a frequent updating of the documents so that they clearly reflect the present wishes of the patient.

Concerning the availability of advance directives, one solution could follow the Danish example with a central archive to be consulted by doctors on relevant occasions. However, this solution seems not to work very well in Denmark. Regular discussions of the matter by the patient and his doctor and, when the patient is incompetent, with his health-care representative and family has been suggested as a more effective way to overcome this problem.

Much needs to be done to change the attitude of doctors about end-of-life decision-making. We have seen that, even if the principle of informed consent is accepted almost everywhere, practice is still rather deficient and doctors often prefer to follow what they consider conforms to good medical practice and

is in the ‘best interests’ of the patient. No blueprint for achieving this goal is available and the question must be seen in the larger perspective of changing views on the role of physicians and the ethic and contents of their profession. Finally, there is the importance of information in the whole process. Looking back over the previous points, it is easy to see this issue cutting across all of them. A vital practice of advance directives requires that both patients and doctors be more adequately informed, patients concerning their rights and the tools at their disposal,⁵⁰ doctors concerning the significance of an advance directive for their legal position vis-à-vis the patient, his representative and his family. Moreover, if both patients and doctors are well informed this should contribute to an improvement in the communication between doctors and patients. This is a fundamental step forward because, in order to be effective, an advance directive should not be simply a legal document, like a will, but should represent the expression of a longer relationship between two parties, patient and doctor, based on mutual trust and understanding. For the patient facing a serious terminal health condition, such a relationship will afford the relief of a sense of serenity. For the doctor, for whom end-of-life decisions are not easy, many problems in the interpretation of the wishes of the patient will become less burdensome.

All these aspects can be summarized in the emerging concept of ‘advance care planning’.⁵¹ Advance care planning can be defined as ‘a structured dialogue [between physician, patient and family] with the ultimate goal that ‘clinical care is shaped by a patient’s preferences when the patient is unable to participate in decision making’.⁵² Interest in advance care planning, as a supplement to advance directives, emerged as a result of disappointment with advance directives, which were seen as often falling short of ‘their goals of aiding decision making and ensuring that patients’ wishes are respected at a time when they can’t participate in decision making’.⁵³

In Teno and Lynn’s view, advance care planning – in which an ongoing, structured dialogue leads to documentation of treatment preferences and a set of contingency plans – can overcome the indeterminacy and inflexibility that advance directives regularly exhibit in practice.

50 As we have seen in section 6.2, proper information can increase the use of advance directives and their quality.

51 See Teno and Lynn, ‘*Putting advance-care planning into action*’, above.

52 *Ibid.*, 205.

53 *Ibid.*

Slipping into normality? *Some Reflections on Slippery Slopes*

Rob Schwitters

1. Introduction

Is allowing euthanasia under specific conditions – as practised in the Netherlands – a social experiment that will finally lead to an unrestricted practice on a large scale? The argument is widely deployed and often referred to as the *slippery slope*-argument. The various supporters of this argument assume that boundary-crossing will take place in varying degrees and directions. Some believe that euthanasia will no longer remain a qualified right of self-determination – as now accepted in Dutch legislation – but will quickly develop into an inevitable trend where in the end every request for terminating life will be honoured.¹ Others believe that the principle of self determination will in time be undermined and that the lives of people whose wishes are not clearly settled will be terminated.² For some it is inevitable that such practices will even slip towards Nazi practices, including the termination of life of people who do not want that.³ Such arguments may often be rejected as suggestive rhetoric but they are not always so easy to disqualify.

In this article I deal with a large category of slippery slope-arguments, the *empirical* slippery slope-arguments, and analyse them in terms of a regular sociological explanation, thus making it easier to distinguish their credentials and flaws. Empirical slippery slope-arguments – as distinct from *conceptual* ones – are akin to a perspective in sociology which explains social processes in terms of unintended consequences.⁴ Formulating them in this way strips them of their rhetorical power and allows us to weigh these objections to a permissive policy against the arguments often offered by their critics, who are just pinpointing the undesirable and perverse consequences of a prohibitive euthanasia-policy. The controversy between those in favour of a permissive policy as against those in favour of a prohibitive policy may thus be put in terms of em-

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- 1 See e.g. Koerselman, F., 'In dodelijke omhelzing?' in: *Als de dood voor het leven, Over professionele hulp bij zelfmoord*, 39-69. Achterhuis, Hans et al. (ed.), Amsterdam, Van Oorschot (1995), 52.
 - 2 E.g. Hendin, H., *Seduced by Death*, New York, W.W. Norton & Company (1997), 47-97; Keown, J., 'Euthanasia in the Netherlands: Sliding Down the Slippery Slope?', in *Euthanasia Examined. Ethical, Clinical and Legal Perspectives*, Keown, J. (ed.), Cambridge, Cambridge University Press (1995), 261-296.
 - 3 Dessaur, C.I., 'Euthanasie: de zelfmoord op zieken en bejaarden' (1985), 15 *Delikt en Delinkwent*, 913-917.
 - 4 Giddens, A., *Social Theory and Modern Sociology*, Oxford, Polity Press (1987), 7-11.

pirical anticipations: what effects might be created by alternative legal regulations?

First, I will define the empirical slippery slope-argument and formulate it in terms of unintended consequences. I will then distinguish two (empirical) slippery slope-mechanisms. One concerns the unintended consequences of social practices, disregarding the way they are introduced by either moral transformations or legal changes. The other concerns the unintended consequences of alternative legal regulation. By pinning down the slippery slope-argument as a sociological explanation and by differentiating alternative mechanisms I will be better able to assess the vulnerability of Dutch euthanasia practice to undesirable unintended consequences.

2. The Empirical Version of the Slippery Slope-Argument

Two versions of slippery slope-arguments, as suggested already, can be distinguished: conceptual (or logical) and empirical (or causal) versions.⁵ In the context of this article only the second version is relevant. Moreover, I have doubts about the soundness of the conceptual version. According to this version, the legalisation of euthanasia (A) conceptually or logically implies the legalisation of morally unacceptable practices in which lives are terminated (B). The idea is that because of the conceptual similarity between practices A and B, once you accept A, you must also accept practice B, a practice which is seen as morally (more) unacceptable. The soundness of this argument, though, may be questioned. How can two cases be conceptually alike, while at the same time be different in terms of one being morally right and the other morally objectionable? Do moral discriminations not demand conceptual discriminations?⁶

The empirical version of the slippery slope-argument tells us that the effect of accepting A, will sooner or later, as a result of social processes, be B, a practice that is morally (more) objectionable.⁷ While the conceptual version

5 The empirical version of the slippery slope is also referred to as the 'causal version'. Because 'causal' suggests a positivistic sociological approach I am somewhat reluctant to use this label. But what will not be lost sight of is that the term 'causal' pinpoints the fact that one will not just register a shift from A to B, but also explain this shift in terms of social processes.

6 There is another version of the logical or conceptual slippery slope argument which is less easy to disqualify. It concerns the problem of grey zones. I will deal with a more empirical version of the grey zone argument later in this article.

7 For coverage of alternative slippery slope-arguments: Beaufort, I. de, 'Op weg naar het einde', in: *Euthanasie, knelpunten in discussie*, G.A. van der Wal c.s. (eds.), Baarn, Ambo (1987), 10-33; Burg, W. van der, 'The Slippery Slope Argument', (October 1991) 102 *Ethics*, 42-65; Griffiths, J., 'The Slippery Slope: Are the Dutch Sliding Down or Are They Clambering Up?' in: *Asking to Die, Inside the Dutch Debate about Euthanasia*, Thomasma, D.C., et al. (eds.), Dordrecht/Boston/London (1998), 93-105; Whitman, J., 'The Many Guises of the Slippery Slope Argument', (1994) 20-1 *Social Theory & Practice*, 85-99; Williams, Bernard 'Which Slopes Are Slippery?', in: *Moral Dilemmas in Modern Medicine*, Michael Lockwood (ed.), Oxford, Oxford University Press (1985), 126-137.

concerns matters of justification ‘you have to admit that’, the empirical version relates to a factual situation ‘it will happen’.⁸

As said, I will exclusively pay attention to the empirical version. In my analysis of this version I will distinguish two mechanisms: the unintended consequences created by alternative legal systems and those produced by the social practice itself, however introduced (by changes in moral climate, legalisation or adjudication). I will discuss the latter category first.

3. The Unintended Consequences of a New Practice

How a new practice is created is irrelevant to many slippery slope-arguments. The practice is taken as a given and the effects are hypothesised as the outcome of the special features of the practice.⁹ In this section I will discuss two such features, *routinisation*, and *social pressure*.

3.1 Routinisation

An objection often raised against euthanasia is that it could lead to doctors getting used to administering lethal drugs and to a diminished respect for human life.¹⁰ Thus, practices seen at first as precarious, might – by being repeatedly pursued – become routinised and lead to an erosion of values. Finally, a situation might result in which the life of patients will be terminated abusively, even against their will.

However, experience in the Netherlands provides no evidence that a permissive policy leads to these unintended consequences. The impression from interviews with Dutch doctors gives no sign of their getting used to it. Nearly all the doctors use words that indicate the precariousness and exceptional nature of the situation, which is nearly always experienced as an emotional burden. The following quotes may illustrate this: ‘Even though I do not talk about it, after I perform a euthanasia several months pass before I can regain my emotional equilibrium’. Another doctor says: ‘The physician’s first job when a patient requests euthanasia, is to find another solution. This is an easy starting point and I believe everyone starts this way because physicians do not like to perform euthanasia; it is a terrible job. From experience, I can say it never becomes easier. Every case of euthanasia is a mountain to climb and the mountain gets higher and higher’.¹¹ That the patient is not just treated as an object

8 Beaufort, I. de, ‘Op weg naar het einde’, above, 12.

9 Burg, W. van der, ‘The Slippery Slope Argument’, above, 54-63, extensively discusses the problems involved with the concept ‘allowing a practice’.

10 The Health Council was formulating this concern: Gezondheidsraad, *Euthanasie. Advies inzake euthanasie uitgebracht door de Gezondheidsraad aan de Minister en de Staatssecretaris van Volksgezondheid en Milieuhygiene*, Den Haag, Staatsuitgeverij (1982), 72.

11 Thomasma, D.C., et al. (eds.), *Asking to Die, Inside the Dutch Debate about Euthanasia*, Dordrecht/Boston/London (1998), 311-313.

may also be concluded from the fact that the better the communication with the patient is, the easier it is for doctors to grant a request. When they must decide on euthanasia with a patient they do not know very well, because they have taken him over from another doctor or department for example, they experience it as difficult.¹²

This considerate attitude could be explained by the relative infrequency with which doctors apply euthanasia. Even in the Netherlands, doctors seldom deal with more than one case every two years.¹³ The fact that euthanasia is not in the hands of specialists, but may be practised by every doctor, is a safeguard against routinisation. Moreover, euthanasia in the Netherlands is, in large measure, practised by general practitioners who know the patient and his/her family well. This does not mean though that the picture of how doctors in hospitals deal with euthanasia is very different. The anthropological studies of euthanasia practices in hospitals of Pool and The also indicate a very prudent and involved attitude from doctors and nurses, an impression of a daily life in which performing euthanasia is not uncommon but those involved never get used to.¹⁴

The evidence provided by the two national surveys (in 1990 and 1995) also proves that decision-making has not become less careful. Increased frequency of consultation and better documentation of cases indicate better decision making over the years.¹⁵ In summary: On the basis of the evidence we have from the Netherlands, it is not possible to conclude that practising euthanasia leads to routinisation and an erosion of values. This may be explained by the low rate of euthanasia practised and the safeguards located in the social context of such practices.

3.2 Social pressure

In the American debate over euthanasia, and in particular *physician assisted suicide* (PAS), a serious objection against legalising these practices is that social inequality will promote their inappropriate use.¹⁶ As long as large groups

¹² *Ibid.*, 337-364.

¹³ *Ibid.*, 491.

¹⁴ Pool, R., *Negotiating a Good Death, Euthanasia in the Netherlands*, New York/London/Oxford, The Haworth Press (2000); The, A.M., 'Vanavond om 8 uur...' *Verpleegkundige dilemma's bij euthanasie en andere beslissingen rond het levenseinde*, Houten/Diegem, Bohn Staf-leu van Lochem (1997).

¹⁵ Maas, P. van der, *et al.*, 'Euthanasia, Physician-assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands, 1990-1995', (1996), 335-22 *The New England Journal of Medicine*, 1705; Wal, G. van der, *et al.*, 'Evaluation of the Notification Procedure for Physician-assisted Death in the Netherlands', (1996), 335-22 *The New England Journal of Medicine*, 1710.

¹⁶ For a good overview of these arguments, see: Battin, M.P., *et al.* (eds.), *Physician Assisted Suicide. Expanding the debate*, Part II, New York, Routledge (1998) 73-163.

In the USA the discussion generally focusses on physician assisted suicide (PAS), and not on euthanasia. In this article I follow the Dutch tradition in which both practices are not seen as morally very different. In the following, the concept of euthanasia includes both.

of patients are without adequate medical care and their illness confronts the next of kin with great financial burdens because of the lack of adequate social welfare and insurance, the danger exists that euthanasia will be requested for undue reasons. There will not be a lot of disagreement on the undesirability of a situation in which the poor, through financial hardship or the denial of medical care, ask a doctor for euthanasia or PAS.

Leaving aside the question of whether one is able to prove the assumed empirical relationship, the structure of the slippery slope-argument is clear and demonstrable. The effect to be proven may be seen as unintended and undesired. Socio-financial pressures make the voluntary nature of the request questionable. The principle that the patient's situation must be hopeless in the sense of there being no alternative medical treatment available, will be undermined if the optimal care available to the better off is systematically withheld from the poor. Where the undesirability of eroding these principles rests on a broad consensus, the slippery slope-argument is a sound argument, provided that it is possible to prove that unintended consequences (that A implies B) do indeed occur.

The slippery slope-argument is much less sound where there is less agreement over the moral desirability of B. It seems reasonable that in the coming years prioritising medical care will become more urgent given the availability of more advanced and expensive medical technology which will exceed the financial capacities of society. In a situation of scarcity, patients dependent on expensive medical care may consider it a virtue to end their lives in order to make medical care available for others. Some will see here the danger of a slippery slope-tendency, others, less convinced that euthanasia for such motives is undesirable, will not. However, more consensus over its undesirability would exist if doctors were to put subtle pressure on some groups of their patients to end their lives because of the scarcity of medical care.

As shown, clear illustrations of slippery slope-tendencies are those in which a social practice B can be seen as the unintended result of the introduction of practice A, and this practice B is seen as undesirable, or at least more undesirable than A. The examples given can be divided somewhat in terms of the degree to which practice B is considered undesirable. All examples, regardless of whether the effects are ascribed to social disparity or to scarcity and the prioritising of medical care, are illustrations of assumed unintended consequences of practice A. One anticipates the unintended consequences which are the result from the manner in which practice A functions in a social context. Such potential slippery slope-effects must be distinguished from the effects of more far-reaching socio-cultural changes, which are often presented in terms of slippery slope-tendencies. Some believe that the practice of euthanasia will not stop at the original boundaries established because of the influences from broad socio-cultural change, such as, for example, the increasing inclination of people to control their own destiny, or due to individualisation processes. The growing inclination for people to control their own destiny will make them

more likely to plan their own death.¹⁷ Individualisation will lead to self determination gaining greater weight so that doctors will be more likely to honour requests to die. The introduction of practice A is seen in this case as part of a broad socio-cultural transformation that will eventually also result in practice B. My point however is, that in this case, it would actually be difficult to assert that B is the unintended consequence of the introduction of A. B might also occur even if one manages to frustrate A. If then you are against B, it would be better to analyse the social structures and try to reform those which appear to change our moral values and sensitivities.¹⁸

It is also questionable whether a B brought about by broad cultural transformations can be considered undesirable. Since it is assumed that the moral standards with which A and B are evaluated will be changed as a result of the same processes that brought about B, to consider B undesirable demands that one disqualifies anticipated moral evaluations. The issue at stake here is whether it is right to try and withstand anticipated moral changes or lead them in another direction. I am eager though, to consider this not very problematic in a society such as ours, in which the moral consequences of specific arrangements of social and economic structures are continually under reflection (consider for example the establishment of labour and social security policy for women's emancipation).

4. The Law and its Unintended Consequences

Until now I have sketched the unintended consequences of social practices without taking into account the manner in which these practices are created. Some unintended consequences have to be ascribed specifically to the fact that it is the law that allows or forbids particular practices. Moreover, the introduction of new practices as a consequence of legal permission is obviously the most realistic example of what 'to allow A' means. It is practically impossible to identify the precise moment a particular social practice can be attributed to changes in moral notions, since such processes take place gradually, at different tempos, in various social groups. But it is possible to unequivocally recognise the 'allowance of A' by a new law or pronouncement of a judge.

Here the main issue is to what degree alternative legal systems create unintended consequences. First I will give attention to a consequence that can only be ascribed to adjudication. Then I will give more focus to the effects of the formation of legal norms irrespective of whether they are brought about by legislation or adjudication.

17 Callahan, D., *The Troubled Dream of Life, Living with Mortality*, New York, Simon & Schuster (1993), 16.

18 Burg, W. van der, 'The Slippery Slope Argument', above, 135.

4.1 Adjudication

Not only the legislature but also the judiciary can take decisions that have far-reaching social impact. Most of the steps towards legalisation in Holland of euthanasia were taken by the judiciary, and the recent legislation can be seen primarily as an ex-post ratification.¹⁹

The casuistic nature of adjudication may result in an unintentional dynamic in the direction of liberalisation. Legislation can better than adjudication adhere to arbitrary criteria for distinguishing the allowed from the not allowed. The legislature can simply assert that if you are driving faster than 50 km an hour then you are driving dangerously, and over a long period of time that criterion can be socially upheld. In the casuist judicial process, in which individual justice and special idiosyncrasies of actual cases play a bigger role, such a longstanding arbitrary fixation of a behavioural standard is far less imaginable.

What we are dealing with here, is a problem that in slippery slope-arguments is often described as a problem of *grey zones*. It refers to the difficulty of qualifying cases that lie somewhere along a continuum with A and B at opposite ends, and where A is seen as morally acceptable and B as unacceptable. An example is the assessment of allowing abortion, where the decision is defined in terms of at what point the foetus can be seen as a human life. A few days after fertilisation (A) that is certainly not the case, at birth (B) it certainly is, but how does one look upon a foetus that is three months old? When it is decided that at three months (*m*) there is still no question of a human life, then what if the foetus is three months and one day old (*n*)? Will the decision be different? In the area between poles A and B is a grey zone where decisions can have a strongly arbitrary character. If you cannot live with this arbitrariness then only a low risk strategy is possible in which either you consider that human life begins at fertilisation – the basis of the most restrictive legislation – or that life begins at birth – the basis for the most permissive legislation.²⁰

Van der Burg has suggested that the casuist method of judges is vulnerable to slippery slope-tendencies. His reasoning is as follows. Unlike the legislature, judges do not formulate a new standard of behaviour at a stroke. They try to come to a result by means of a multitude of small interpretative modifications, each by themselves hardly noticeable. A judge therefore may then accept that a great difference exists between A and B: Once he accepts A, a precedent is created, which, according to Van der Burg, makes it more likely that he will accept a more permissive *m*, which then clears the way for the acceptance of *n*.²¹ What strikes me as debatable with this reasoning is why a judge oriented to the most recent precedent *m*, does not with just as much right take a step backwards towards (a more restrictive) *l*, so that *l* functions as precedent for a subsequent decision. The dynamic in the direction of B, considered thus, is not at all inevitable.

19 See Weyers, H., 'Euthanasia: the Process of Legal Change in The Netherlands', in this Issue.

20 Burg, W. van der, 'The Slippery Slope Argument', above, 50-51

21 *Ibid.*, 50

The possible inevitability of this dynamic is only understandable if one considers other aspects of adjudication. A leading principle in criminal law is that people must be able to manage their lives within the framework of the law (the legality principle), the idea being that people should not be punished if they do not have the opportunity to anticipate the rules they must uphold.²² For the judge this means that each decision that is more restrictive to a relevant precedent is precarious, since in that case people would be punished who expect to act within the boundaries of the law. For example, if the judges were to extend the concept of unbearable suffering to include mental illness, then it would be very difficult to be more restrictive later. Doctors could be punished who had orientated themselves on most recent jurisprudence.

This principal of legality is probably particularly relevant in judging questions of euthanasia, since in many such cases the motivations of the criminal offenders, the doctors (in contrast to those of many other criminal offenders) are seen as honourable. The tendency towards more permissive decisions seems most probable though, in countries where the judge has no discretion in sentencing. In the Netherlands these tendencies are mitigated by the fact that the judge has the opportunity to limit himself to the imposition of a symbolic sanction.

This vulnerability of adjudication to a tendency in a more permissive direction may explain why in many countries with restrictive regulations on euthanasia, there is little inclination to prosecute euthanasia practising doctors. When their behaviour will be dealt with in a judicial procedure, it is difficult not to affect restrictive norms.

5. The Unintended Consequences of Alternative Legal Regulation

In what follows, I will bypass the question of whether social practices are the result of adjudication or legislation. I will focus rather on the diverse unintended consequences of restrictive and permissive legal regimes respectively, whether based on adjudication or legislation.

Comparing the unintended consequences of both restrictive and permissive legal regimes, I will focus in particular on two qualities that are especially relevant. To what degree may the *transparency* of euthanasia-practices contribute to improved legal control of these practices? To what degree are distinctions which differentiate allowed from not-allowed behaviour, *effective distinctions*?

5.1 Transparency

The thesis that a legal regime that allows euthanasia will inevitably lead to abusive practices is not supported by empirical evidence. Comparative evi-

22 Hart, H.L.A., *Punishment and Responsibility, Essays in the Philosophy of Law*. Oxford, Clarendon Press (1968) 177-185.

dence from the Netherlands, Australia, and Flanders (Belgium) indicates that the most permissive, Dutch regime, shows the lowest prevalence of abusive practices, at least where abusive practices are defined as those not based on a well considered request to terminate life. In the Netherlands (1995) this category consisted of 0.7%, in Flanders (1999) 3.2% and in Australia (1996) 3.5% of all cases of death.²³ These figures however give little insight into possible slippery slope-tendencies since that requires evidence of the prevalence of practices at different moments. If one compares the Dutch nationwide surveys of 1990 and 1995, however, then there is a decrease from 0.8 to 0.7%. If a comparison of those studies gives any reason to fear undesirable consequences then that can only be that the extent of regular euthanasia practices (ending life with the help of lethal medicine on the basis of an explicit request) has increased from 1.9% to 2.6%.²⁴

Many explanations have already been suggested for the apparently superior capacity of the Dutch legislation to reduce abusive practices. Let me recall just a few.²⁵ First, only a legal system that allows euthanasia is able to develop requirements of careful practice. The Netherlands is the only jurisdiction to have formulated many substantive and procedural requirements. In this sense the qualification of Dutch policy as permissive is misleading. Second, an unintended and undesirable consequence of a legal system that considers euthanasia illegal is that such practices are forced underground. Out of public view these practices can no longer be subject to substantive and procedural requirements. Also in this respect the more transparent Dutch policy seems more effective. In the period between the two nationwide surveys undertaken in 1990 and 1995, euthanasia practices became more in accordance with standards of care.²⁶ Third, where euthanasia is legalised, doctors are able to give more attention to the wishes of their patients concerning the way in which they want to die. In countries with a regime that bans euthanasia such questions are not brought into the open. By implication the question of terminating life is often only brought up when the patient is no longer competent. This is one of the explanations why in countries such as Belgium and Australia a termination of life without a request is more often practised than in the Netherlands.²⁷ Finally, a

23 Maas, P. van der *et al.*, 'Euthanasia, Physician-assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands', above, 1699-1705; Kuhse, H., *et al.*, 'End-of-life decisions in Australian Medical Practice', (1997) 166 *Medical Journal of Australia*, 191-196; Deliens, L., *et al.*, 'End-of-life Decisions in Medical Practice in Flanders, Belgium: a Nationwide Survey' (2000) 356 *The Lancet*, 1806-1812.

24 Maas, P. van der, c.s., 'Euthanasia, Physician-assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands, 1990-1995', above, 1701.

25 See: Otowski, M., 'The Effectiveness of Legal Control of Euthanasia', and Mortier, F. and Deliens, L., 'The Prospects of Effective Legal Control of Euthanasia in Belgium', in this Issue; Griffiths, J., 'The Slippery Slope: Are The Dutch Sliding Down or Are They Clambering Up?', above, 90-105; Kuhse, H., 'From Intention to Consent', above, 252-267.

26 Maas, P. van der, c.s., 'Euthanasia, Physician-assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands, 1990-1995', above, 1699-1705.

27 Otowski, M., 'The Effectiveness of Legal Control of Euthanasia', and Mortier, F. and Deliens, L., 'The Prospects of Effective Legal Control of Euthanasia in Belgium', in this Issue; Kuhse, H., 'From Intention to Consent', above, 252-267.

permissive legal regime stimulates an open climate in which involved organisations (such as the KNMG²⁸) have the chance to actively participate in the formulation of relevant requirements. This has a positive effect on their contribution to the enforcement of requirements. This informal enforcement is crucial for the effectiveness of the regulation of euthanasia, since those practices are very inaccessible for the prosecution authorities.²⁹

5.2 Transparency reconsidered: the instrumental versus the communicative dimension of law

Is a legal regime that bans euthanasia doomed to failure? Shouldn't those who are opposed to allowing the practice of euthanasia, be convinced of the idea that if they want to stop abusive practices a permissive regime shall be preferred? Choose A when you want to avoid B even when you actually have moral objections to A? This argument is the opposite of the slippery slope-argument brought forward by opponents of permissive regimes. It is an argument in which A is not evaluated in its own right, but in terms of the assumed implication, being that it will stop B.

I want to mention here a few objections against arguments in which the independent evaluation of A barely plays a role. These objections are inspired by an approach to law formulated in recent years by legal theorists in Tilburg, who are accentuating the communicative dimension of law. Central to their approach is the idea that the effectiveness of law is very much dependent on the degree in which the legally formulated norms are persuasive for their addressees. The rationale which underlies this approach is that often, persuasion is a more effective instrument than a strict enforcement accompanied by punishment. A legislator aware of the communicative dimension of law should give priority to information campaigns and promote structures of deliberation in which the addressees of law are given the opportunity to participate in the formulation and interpretation of the legal norm. Such participation is expected to have a positive effect on the enforcement of the norm.³⁰ Although the Tilburg legal theorists are especially concerned with aspirational norms such as equality or due process, which involve a more far-reaching realization than a strict compliance with legal rules, their approach is also relevant for problems concerning the effectiveness of law in a more restricted sense.

28 Weyers, H., 'Euthanasia: the Process of Legal Change in The Netherlands', in this Issue. See also: Griffiths, J., 'Self-regulation by the Dutch Medical Profession that Potentially Shortens Life', in: *Regulating Morality: A Comparison of the Role of the State in Mastering the Mores in the Netherlands and the United States*, Krabbendam and Napel, H. M. ten (eds.), Antwerpen/Apeldoorn: Maklu (2000), 173-190.

29 Griffiths, J., Bood, A., & Weyers, H., *Euthanasia and Law in the Netherlands*, above, 236.

30 Witteveen, W., 'Significant, Symbolic and Symphonic Laws', in: *Semiotics and Legislation. Jurisprudential, Institutional and Sociological Perspectives*, Schooten, H. van (ed.), Liverpool, Deborah Charles Publications (2000), 27-70; Klink, B. van, 'Summary', *De wet als symbol*. Deventer, W.E.J. Tjeenk Willink, 439-446.

It is difficult to establish whether legalisation of euthanasia in the Netherlands should now mainly be seen as the result of an instrumental policy orientated on the reduction of abusive practices (B) or the result of a positive evaluation of A in its own right, an approach which is more informed by the communicative qualities of law. It is not difficult to find arguments which express an instrumental policy approach. An example is found in the report of the Health Council in 1982, which pointed to the disadvantages of a restrictive legal regime in which:

The state forbids euthanasia and assistance with suicide but in practice doctors do perform euthanasia under certain circumstances, and they do in certain cases supply the means with which a person can kill himself, without in fact exposing themselves to criminal prosecution. This situation is objectionable in several respects. The fact that doctors who, in certain cases, are prepared to perform euthanasia and to assist with suicide, and who actually do so, are not exposed to criminal prosecution is simply a result of the fact that they give their help 'behind closed doors', so that no charges can be filed against them. All this leads to disingenuous representations of what has taken place that are completely uncontrollable. When medical practice takes place out of public view, furtively, it is impossible to know whether the doctor acts conscientiously.³¹

It is not difficult to find more indications that an instrumental perspective, having regard to the unintended consequences of a prohibitive law, may have contributed to the Dutch permissive regulation. But its role shall not be overestimated since the legal regulation has been brought about step by step by the judiciary. Adjudication appears to be less receptive to instrumental policy considerations than legislation.

More study is required for a better insight into the main considerations shaping Dutch policy and law regarding euthanasia,³² but it can be said with more certainty that the communicative dimension is rather significant in the way euthanasia is regulated in practice. Thus, Griffiths underlines how important it is for the effectiveness of procedural and substantive requirements that doctors and their organisations are involved in formulating the norms.³³ Another aspect of Dutch euthanasia regulation that supports the communicative dimension is the fact that in the most recent regulation of the notification procedure, the criminal law is deliberately placed at a distance. In the first instance, a multidisciplinary committee assesses the reported practices and the emphasis in the assessment is more on responsibility and education than on deterrence and punishment.

³¹ Gezondheidsraad, 'Euthanasie', above, 86-88.

³² Forthcoming in dissertation H. Weyers.

³³ Griffiths, J., 'Self-regulation by the Dutch Medical Profession that Potentially Shortens Life', above, 173-190.

The importance of the moral support legal rules receive among doctors and their organisations has been shown in this Issue by Mortier and Deliens. They doubt the effectiveness of the proposed Belgian bill, which leans heavily on the Dutch legislation, as long as the doctors themselves do not see the value of the proposed requirements of careful practice. In a climate that is antagonistic towards any political and legal intervention in their domain, and where doctors have not internalized norms such as informed consent and self determination in their daily practice, enforcement of the law will be more problematic than in the Netherlands. Seen from a communicative perspective, the law may not be persuasive enough. It is the same communicative dimension that explains why a restrictive regime is not doomed to failure in all countries. Tentative evidence from Norway indicates that a euthanasia prohibiting norm can be effective. Of crucial importance is that the prohibition has broad support among doctors and their organisations.³⁴ By the same token, the effectiveness of the permissive legislation of the Netherlands is also based on a broadly shared acceptance of euthanasia, and the conviction that the procedural requirements have an intrinsic moral value.

A perspective which focuses on the effectiveness of law has to pay attention to its communicative dimension.³⁵ An instrumental approach which neglects the communicative dimension may become derailed. Imagine a euthanasia policy that makes the substantive requirements completely subordinate to the realization of transparency. The structure of such an argument shows a striking similarity to the slippery slope-argument. It requires one to abstain from an evaluation of A (a more permissive legislating of euthanasia) in its own right but to evaluate A from the perspective of the anticipated effect: increasing transparency and presumably better control of abusive practice B. The weakness of such an approach is that as long as the new introduced legal norms do not receive moral approval among doctors, new hidden practices will arise in the shadow of each newly introduced norm. The introduction of a new, more permissive, norm will be interpreted by some doctors as legitimising practices that are just across the legal boundaries. This phenomenon of shadow practices is especially applicable to acts such as euthanasia, where there is no consensus in which circumstances it is allowed. Being aware of the flexibility of the law and the open climate, doctors with a more permissive attitude to euthanasia will not hesitate to carry out their liberal practices. But as long as they consider themselves to be acting illegally, they will do so out of public view. As long as the legal authorities are fixated on transparency, they will be eager to introduce still more permissive standards. It is like a cat chasing its own tail.

34 Førde, R., *et al.*, 'The Ethics of Euthanasia-attitudes and Practice among Norwegian Physicians', (1997) 45-6 *Social Science and Medicine* 887-892.

35 This dimension is integrated in the model of 'The Social Working of Law', developed by Griffiths, that has a strong orientation to the effectiveness of law. See: Griffiths, J., 'De Sociale Werking van Recht', in: *De Sociale Werking van Recht*, Griffiths, J., Nijmegen, Ars Aequi Libri (1996), 469-513

The gist of my argument is that the realization of transparency cannot be the only perspective that determines the regulation of euthanasia, to the exclusion of other values. Only if the striving for transparency is integrated with a policy of persuading the addressees of the appropriateness of the formulated legal norms may it lead to an effective policy.

5.3 Effective distinctions

Clear distinctions may serve as a barrier against an unintentional expansion of social practices. Examples would be allowing abortion only when the foetus is younger than twelve weeks, denying life-sustaining treatment to babies born younger than twenty-five weeks, or not allowing IVF for women older than forty years. Clear distinctions give unambiguous guidelines to mutual expectations, to those, for example, involved with the formal and informal enforcement of the norms. In this respect, the argument that a ban on doctors administering or providing lethal drugs might serve as a safeguard against slippery slope-tendencies, has some plausibility.

The distinction, Bernard Williams suggested, between *reasonable* and *effective* distinctions is enlightening.³⁶ Reasonable distinctions are those founded on moral considerations, such as there can be good moral reasons for the termination of life on request and not allowing it if this request is lacking. That a distinction is reasonable does not necessarily imply that it is simple to enforce, that is to say effective. It is precisely the point of many slippery slope-arguments, that even when there are sound moral grounds for distinguishing A from B, a legal regulation may be an ineffective distinction, because it is incapable of enforcement.

May a law that prohibits doctors to provide or administer lethal medicines be an effective barrier against the expansion of euthanasia practices? As shown earlier, only when this ban finds the support of the relevant groups involved, in this case especially doctors and pharmacists. In its unambiguity, a ban is in any case a clear orientation point for mutual expectations. This does not exclude the fact that administering pain-relieving medicines can mask an intended termination of life. But the most recent insight is that it is possible to assess objectively what dosage of medication is required to relieve the pain and that an adequate dosage only incidentally will have a life shortening effect.³⁷ The rule that the shortening of life by the administration of drugs is only acceptable as long as this is informed by the aim of pain relief, may put a clear and unambiguous boundary against an unfettered movement in the direction of a more expansive practice.

36 Williams, B., 'Which Slopes are Slippery?', in: *Moral Dilemmas in Modern Medicine*, Michael Lockwood (ed.), Oxford, Oxford University Press (1985), 126-137.

37 Admiraal, P. and Griffiths, J. 'Sterven aan pijnbestrijding', (2001) 56-2 *Medisch Contact*, 463-467.

Can the requirement of a well-considered request not constitute a clear boundary and provide an effective safeguard against the development of abusive practices? If abusive practices are defined as the un-requested termination of life, that is apparently – as the earlier presented data suggests – the case. It ensures that doctors are orientated to getting the patient's approval. It is, however, less certain whether the requirement of a well-considered request itself will not be undermined by social tendencies. A patient's request may be determined by hard to trace social pressures and by standards of socially desirable behaviour.

Even if we presume the requirement of a well-considered request to be a rather appropriate safeguard against terminating the life of patients against their will, it may still be discussed if it is in all respects an effective distinction. This requirement cannot of itself be a safeguard against an unintended development in which all requests in the end will be honoured without further qualifications. As I have already mentioned, a well considered request is not the only requirement for the legal practising of euthanasia in the Netherlands. Not all well considered requests are honoured. The patient's suffering must be unbearable and his or her situation must be hopeless. These principles together justify the application of euthanasia. In brief, what it amounts to is an application of a combination of the basic principles of autonomy and mercy, the duty to alleviate pain or ease suffering. They are applied together so that a more flexible interpretation of the one condition is compensated by a more rigorous interpretation of the other. Nevertheless, one might raise the question whether the application of these requirements in concert may serve as an effective safeguard against unintended tendencies? Even if the requirement of a well considered request is able to ban tendencies in the direction of the involuntary termination of life, it does not preclude the possibility of the increasing marginalisation of the supplementary requirements, a development that can eventually result in every request being honoured.

Social changes such as individualization are strengthening principles of autonomy, self-determination and informed consent, a development that might undermine the relevance of the supplementary requirements. That in legal discussions of euthanasia, unbearable suffering is increasingly seen as a subjective matter, may be seen as an indication of this tendency.³⁸ Another indication is that for the assessment of a patient's situation as being hopeless, it is sufficient that the patient rejects available forms of treatment. Hopelessness does not require the factual unavailability of alternative treatments. These developments suggest that in the appraisal of euthanasia practices, the principle of autonomy is gaining increasing significance.

The question remains, however, how far can one expect legal rules to stop social cultural changes? Even a euthanasia prohibiting law would, in the end, not be able to survive these changes. When developments are going in direc-

38 E.g. *Rechtbank Haarlem* 31 October 2000, in its assesment of the 'Brongersma case'. The judge considered that unbearable suffering is to a great extent a subjective and difficult to objectify attitude to life.

tions that make new and completely different boundaries or distinctions reasonable, then each distinction, even if it is easy to enforce, finally will collapse. In fact, such developments lie outside the scope of argumentation in terms of slippery slope- tendencies.

More directly relevant for tracing unintentional consequences of the introduction of social practices is the significance a juridification of euthanasia may have for the distinction between acceptable and unacceptable behaviour. In the Netherlands, the practice of euthanasia is more than in any other country a target of legal regulation. There is no country in which such clear substantive and procedural guidelines have been developed, no country where the practice of euthanasia is so visible to the legal authorities and where euthanasia has been the subject of so many judicial assessments. This juridification implies that many of the idiosyncrasies in the richly interwoven and complex social relations found in the medical setting (such as the doctor-patient, doctor and patient's family relationship) have been translated and transformed into legal concepts. It may be questioned whether this transforming process itself unintentionally creates more room for carrying out the practice of euthanasia.

Further investigation is needed of the precise effects of juridification, but I will suggest one example. In the medical context, unbearable suffering is generally an indication for extra treatment (more or different medicine, or perhaps an operation). In this context, it has a certain degree of objectivity: it is relative to a particular treatment that can be more or less successful because the result can be retrospectively evaluated. In the legal context of euthanasia the concept of unbearable suffering seems to acquire a more subjective character. In this context, it does not qualify the patient for alternative medical treatment but for the legitimate ending of his life. What is at stake is how much one must suffer before being able to get one's life terminated by a doctor. This question is much more difficult to judge, not least because the result of the treatment cannot be tested objectively. Perhaps the effects of the process of juridification on the conceptualization of unbearable suffering may explain why only in the Netherlands the question whether suffering of ageing may be seen as unbearable suffering, which in other countries would be anathema, can be a serious theme of judicial consideration.³⁹

6. Concluding Remarks

As other commentators have suggested: the slippery slope-argument 'is itself a bit of a slippery customer, hard to pin down, usually more a bit of suggestive rhetoric than a serious argument'.⁴⁰ Translating the empirical version of this argument in terms of a sociological analysis of unintended consequences, results in the argument being stripped of its rhetorical overtones and it being rep-

39 Gerechtshof Amsterdam 8 May 2001 ('Brongersma').

40 Griffiths, J., 'The Slippery Slope: Are The Dutch Sliding Down or Are They Clambering Up?', above, 90.

resented in the form of a thesis more amenable to evaluation. Moreover, by taking the unintended consequences of action as central to the argument, attention becomes somewhat less one-sided on the undesirable effects of allowing new practices, and provides an opportunity for a discussion also of the unintended effects of a regime that prohibits those practices.

In this article I have just suggested a thesis which can be empirically tested, not presented unequivocal empirical evidence. However, on the basis of the existing empirical findings it can be postulated with fairly strong certainty that the Dutch experiment with a permissive euthanasia policy is unlikely to be derailed. Euthanasia has in no way become a routine procedure for Dutch doctors making them lose all their reserves against giving lethal medicine. Moreover, there is no other country where the practice of euthanasia is subject to such extensive substantive and procedural requirements.

Restrictive regimes appear to be more vulnerable to abusive practices, which is mainly due to a lack of openness and too little emphasis on self-determination. Despite this, it is difficult to come to generalised conclusions about the advantages and disadvantages of permissive and restrictive judicial regimes, because of the significance of the role of the medical profession. Tentative evidence from Norway suggests that it is possible for a restrictive proposal to stop the practice of euthanasia as long as the ban is acknowledged and upheld by doctors and their organisations.

It is the more effective legal regime which explains why the Netherlands is less vulnerable for a slip into abusive life-terminating practices. If the Dutch legal regime is vulnerable to unintended consequences at all, then it lies in the inherent limitations of the requirements of legally justified euthanasia to limit the practice to desirable cases. The application of the various substantive requirements leads to more open boundaries than would be the case if an absolute ban on providing or distributing lethal medication would be effectively enforced. It is obvious that these boundaries are unlikely to resist wider social changes in values and moral sensitivities. The individualisation process taking place in society may, for example, stretch these limitations. But, as said earlier, it may be asked also if an absolute ban on the administration or distribution of lethal medicines can ward off such changes any better.

There is, however, a further reason for concluding that the distinctions enforced in a permissive legal system may be more vulnerable for unintended net-widening than the enforced requirements of a restrictive system. Firstly, the growing need to prioritise medical care means that for some individual patients, ending life might be seen as socially desirable behaviour. It could also result in doctors putting subtle pressure on their patients. Secondly, it has been suggested that stretching these boundaries may be contained in the legal character of the decision-making itself. Thus, adjudication may have the unintended tendency to move in the direction of relaxing standards of behaviour. But most signs seem to indicate that in the Netherlands the management of euthanasia is not resulting in abusive practices. If it is slipping, it is 'only' slipping into normality.

The Quest for Limits

Law and Public Opinion on Euthanasia in the Netherlands

Margo Trappenburg and Joop van Holsteyn

1. Introduction¹

One of the recurring worries about Dutch euthanasia policy is that over the years it almost seems as if nothing is taboo. The Dutch have pondered the permissibility of terminally ill cancer patients. They have discussed the medical shortening of life for elderly patients suffering from Alzheimer's disease. They have debated the fate of permanently comatose patients. They have talked about psychiatric patients who are determined to take their own lives. They have questioned whether minors are entitled to decide for themselves about their own life and death. And they have debated the concerns of elderly people who do not want to wait for natural death to collect them. Obviously, however, discussion or even extensive debate does not imply public acceptance.

The starting point to find out what is and what is not permissible in the Netherlands is the new legislation on medical assistance in dying and the parliamentary proceedings concerning this new law.² In addition to legal permissibility, the second step might be to search for medical acceptance and its limits. This might be found in the statements and official reports issued by the medical profession and its organizations, most prominently the Royal Dutch Medical Association (KNMG) but also the associations for psychiatrists or nursing home physicians. The Dutch law has been characterized as the result of 'a process of self-regulation [by the medical profession] which has been going on for more than twenty years already'.³ Griffiths has done extensive research into the norms and regulations surrounding euthanasia in the Netherlands. He has observed that 'the rules that now apply to euthanasia emerged within the medical profession itself and were later adopted by the courts in the context of criminal prosecutions. The courts – especially the Supreme Court – have formulated the defense of justification available to a doctor in a way that explicitly acknowledges the primacy of medical ethics and professional standards'.⁴

1 We benefited from comments on an earlier version by Govert den Hartogh, Henri Wijsbek and other members of the euthanasia research group.

2 Cf. www.minbuza.nl/original_documents/c_55024.pdf.

3 Griffiths, J., 'Self-regulation by the Dutch Medical Profession', in: *Regulating Morality. A Comparison of the Role of the State in Mastering the Mores in the Netherlands and the United States*. Krabbendam, H. & Napel, H.-M ten (eds.), Amsterdam/Apeldoorn, E.M. Meijers Instituut & Maklu Uitgevers, (2000), 173-190 [177].

4 *Ibid.*

The medical profession in the Netherlands is very well organized; almost all medical doctors are members of the Royal Dutch Medical Association (KNMG). Hence, one may reasonably assume that most of them share the views pronounced by their organization. This being the case it seems likely that the criteria for acceptable euthanasia enacted in the law will tend to concur with the limits drawn by doctors.⁵

The third place to look for the boundaries between acceptable and unacceptable forms of euthanasia is public opinion. Where do ordinary Dutch citizens draw the line and does this line correspond with the boundaries that are laid down in the law and the accompanying parliamentary proceedings? This question on public opinion concerning different forms of euthanasia is the central question that we address in this article. We will focus on the substantive criteria in the new law – i.e. the existence of unbearable suffering, and a voluntary, well-considered request – thereby assuming that ordinary citizens are less interested in procedural criteria such as the consultation requirement and the notification procedure.

2. Method and Data

In January 2001, we sent a self-administered postal questionnaire to a random sample of 2500 households in the Netherlands.⁶ The sample was provided by the Postal Office. In an accompanying letter we introduced the survey and described the procedure for drawing a sample within the household. The questionnaire was to be filled in by a person 18 years of age or older, more specifically by the person in the household whose birthday would first follow the receipt of the questionnaire. One week after sending the questionnaire a reminder was sent. Because of a lack of funds only a letter was sent, and not a new questionnaire. A total of 1027 questionnaires were returned of which 991 were filled in completely, a net response of 39.6 percent. The survey in 2001 was to a large extent a replication of a survey held in 1995; the net response in the initial survey on euthanasia was 46 percent (of a sample with size 2000). In both years a comparison of the respondents with the Dutch population as a whole on known characteristics as sex and religion showed only minor deviations. For example, the Dutch population consisted of 49.5 percent male and 50.5 female citizens in both 1995 and 2001;⁷ in the sample these percentages were 52.3 and 47.7 percent and 49.7 and 50.3 percent respectively. With regard to religion, in 1995 33 percent of the Dutch population was of Roman-

5 One criterion that does not seem to meet wholehearted acceptance in the medical profession is the notification procedure. Cf. Griffiths, J., Bood, A. and Weyers, H., *Euthanasia and Law in the Netherlands*, Amsterdam, Amsterdam University Press, (1998) 237. There is also some doubt whether nursing home physicians are happy with the prominent status of advance directives in the new law.

6 The survey was supported financially by the Leids Universiteits Fonds (LUF). We would also like to thank Berlinda Wagenaar for her assistance in creating the data set of the 2001 survey.

7 CBS, *Statistisch Jaarboek 2001*, Voorburg/Heerlen, CBS (2001) 30.

Catholic persuasion, 14 percent was Dutch Reformed, 7 percent was Calvinist (*Gereformeerd*), 7 percent was of some other religious group and 40 percent did not have or admit to adhere to any denomination or religion; in the 1995 sample the percentages were 29, 13, 7, 5 and 46 percent respectively. In 2001 percentages for the population were 31, 14, 7, 8 and 41, while in the 2001 sample there were 25 percent Roman-Catholics, 11 percent Dutch Reformed, 4 percent Calvinist, 9 percent 'Other' and 51 percent without a conviction or religion.⁸ Although there are slight deviations in our samples from the population, we think that our samples of 1995 and 2001 may be considered sufficiently representative of the population as a whole. Because of this we did not weight the data presented in this article.

Both in 1995 and in 2001 most of the questions on euthanasia were cast in the form of so-called vignettes, i.e. sketches or scripts of various situations in which some form of euthanasia was suggested or carried out. 'The advantage behind their use is that (...) vignettes present the respondent with concrete and detailed situations. It becomes possible, therefore, to discuss norms and beliefs in a situated way which accepts the complexities normally surrounding them'.⁹ Most sketches in our questionnaire were followed by several approval/disapproval statements with which the respondent could (fully) agree or (fully) disagree on a seven-point Likert type scale. Respondents were offered the explicit option of 'no answer/no opinion'. The presence of a 'neutral' mid-point (4) on a seven-point scale does not make this option redundant and 'it is important not to confuse the option 'don't know' or 'no opinion' with an intermediate option, for example between 'agree' and 'not agree''.¹⁰

All vignettes in the questionnaire were based on or inspired by real life situations, i.e. actual cases of euthanasia in the Netherlands. The survey of 2001 was meant to be a replication of the original survey of 1995, but we also added some new questions (vignettes) in 2001 as a result of the most recent developments with regard to the practice of euthanasia in the Netherlands.

3. Results: Opinions on Euthanasia

3.1 Euthanasia in its most common form

In most cases of euthanasia in the Netherlands the patient requesting euthanasia is suffering from cancer or some other gruesome physical ailment such as multiple sclerosis or a progressive muscular disease.¹¹ In both the 1995 and

⁸ See for population figures on religion: *Ibid.*, 48.

⁹ Lee, M.L., *Doing Research on Sensitive Topics*, London, Sage etc. (1993) 114.

¹⁰ Dijkstra, W. & Smit, J., *Onderzoek met vragenlijsten. Een praktische handleiding*, Amsterdam, VU Uitgeverij (1999), 100 [our translation]; cf. Schuman, H. & Presser, St., *Questions and Answers in Attitude Surveys. Experiments on Question Form, Wording, and Context*, San Diego, Academic Press (1981).

¹¹ In 1995 80 percent of the patients dying as a result of euthanasia suffered from cancer, 4 percent from neurological diseases. Van der Wal, G.A. & Maas, P.J. van der, *Euthanasie en an-*

2001 questionnaire we included a general question on euthanasia in this most common variety. The general question we started with, reads:

General Question

Euthanasia is the termination of life by a doctor after repeated requests by a terminally ill patient. Some persons feel that euthanasia should be forbidden under all circumstances. Others feel that a doctor should always be allowed to perform euthanasia at the request of the patient. And, of course, there are those whose opinion lies between these two positions

The answers are presented in table 1.¹²

Table 1. General opinions towards euthanasia, 1995 and 2001

Question:

What is your opinion? Could you place yourself on the [7-point] scale below?

	1995	2001
(1, 2, 3)		
always forbidden	12%	12%
4	8	10
always allowed		
(5, 6, 7)	77	75
don't know/no answer	3	4
Total	100%	101%
N=	911	991

Note: differences for 1995 and 2001 are not statistically significant (at .01).

The general attitude question on this form of euthanasia was followed by a vignette that described the case of Mr. Bootsma, an example of this type of euthanasia. The results are presented in table 2.

Mr. Bootsma

Mr. Bootsma has an incurable muscle disease. He is no longer able to walk. Speech is becoming increasingly difficult. The disease will cause more and more paralysis and the chance is great that in about two months he will suffocate. Bootsma has repeatedly told his wife and his physician that he does not wish for things to go that far. He would like for the doctor to help him die. Bootsma's physician consults with another doctor and then provides Bootsma with a lethal injection.

Over the years euthanasia in the case of terminally ill patients – in particular those suffering from cancer or some other physical ailment – has become relatively unproblematic. Euthanasia in this classical or common form is generally accepted in the Netherlands. Only a small minority of Dutch citizens of 12 percent (see Table 1) opposes euthanasia even in this most common form.¹³

dere beslissingen rond het levenseinde. De praktijk en de meldingsprocedure, Den Haag, SDU (1996) 54.

¹² Due to rounding error percentages may not always sum exactly to 100.

¹³ The results of these questions in our survey concur with other opinion research in the Netherlands. The Social and Cultural Planning Bureau (SCP) found on the basis of several surveys

**Table 2. Opinions towards euthanasia.
The case of Mr. Bootsma, 1995 and 2001**

<i>Question:</i>		
Do you think that Bootsma's physician has acted correctly?		
	1995	2001
Yes	76%	82%
No	16	12
don't know/no answer	8	6
Total	100%	101%
N=	911	991

Note: differences for 1995 and 2001 are statistically significant (at .01).

However, an overwhelming majority of about 75 percent agrees that doctors should be allowed to accede to the well-considered request of an incurably ill patient who is suffering unbearably, to end his life. We see this kind of a majority if we look at the very general question on euthanasia (Table 1) as well as in the particular case of physician-assisted death of Mr. Bootsma (Table 2).¹⁴ In the case of Mr. Bootsma the acceptance of euthanasia appears to have become even more widespread in 2001 than in 1995. The rise in acceptance is small, but statistically significant.

3.2 Psychiatric patients

Although dying patients who suffer from some terminal physical ailment are by far the largest group of patients requesting euthanasia, they are not alone. On occasion other cases of euthanasia or medically assisted suicide have attracted media attention. In June 1994, for example, the Dutch Supreme Court ruled in what became known as the Chabot case.¹⁵ Mrs. Boomsma was the patient in this case. She was a middle-aged woman, whose marriage had never been very happy and had ended in divorce. Her elder son committed suicide while he was in military service. Her younger son suffered from cancer and had also died. Thereafter Mrs. Boomsma found that she had nothing left to live for. All she wanted was to die and to be buried between her two sons. So she

with differently worded questions that 10 to 16 percent of respondents reject euthanasia in whatever form or shape. *Sociale en culturele verkenningen 1997*, Rijswijk, SCP (1997) 163.

14 It should be noted that the Netherlands is not unique in its broad acceptance of this form of euthanasia. In countries such as America and Canada support for euthanasia or physician assisted suicide appears to be widespread as well. According to Gallup polls, for example, in the 1990s 75 percent or more of the respondents agreed with the following question: 'When a person has an incurable disease that causes great suffering, do you, or do you not think that competent doctors should be allowed by law, to end the patient's life through mercy killing, if the patient has made a formal request in writing?' (www.ves.org.uk/DpSur_USACan.html, October 2001) Even earlier majorities were in support of euthanasia (Ostheimer, J.M., 'Changing attitudes toward euthanasia', (1980) 46 *Public Opinion Quarterly*, 123-128).

15 The Chabot case is described in Griffiths, J., A. Bood & H. Weyers, *Euthanasia and Law in the Netherlands*, above, 329-340.

contacted psychiatrist Chabot and asked him to help her end her life. After numerous conversations Chabot finally decided to help her. He gave her medication to enable her to commit suicide.

The Chabot case raised two important legal and moral issues:

- 1) Can the suffering of psychiatric patients be unbearable and without any prospect of improvement? If so, is it acceptable for doctors to assist them in suicide?
- 2) Is it acceptable for a doctor to help people take their own life because they are very unhappy and desperate, even if they do not suffer bodily?

The Supreme Court had to deal with both these questions. The first question was answered affirmatively. According to the Supreme Court in exceptional cases psychiatric patients may be given assistance in suicide. However, doctors who go along with such a request must be extremely careful and take even more precautions than doctors who administer 'ordinary' euthanasia. This ruling of the Supreme Court was in line with the position taken and defended by the Royal Dutch Medical Association (KNMG) in a report on psychiatric patients.¹⁶ This report on euthanasia in the Netherlands suggested that assistance in suicide to psychiatric patients occurred no more than ten times per year, although several hundreds of psychiatric patients ask their psychiatrists to help them take their own lives.¹⁷

There was a complicating factor, however. Chabot maintained that Mrs. Boomsma had *not* been a psychiatric patient at all. In fact, this evaluation of her case had been a contributing reason for his decision to honor her request. After all, psychiatric patients do not always know very well what they want, since their disease may seriously cloud their judgment. Mrs. Boomsma, on the other hand, knew exactly what she wanted and she certainly did not want to be viewed as a patient in need of therapy. She was extremely disconsolate and she simply had not recovered, nor did she wish to recover, from the death of her sons. Nor did she wish to change herself.¹⁸ This raised the very important question whether people who do not qualify as 'patients' in any normal sense of that word – because they do not suffer from a disease or an illness – should receive medical assistance for suicide.

Unfortunately, the Supreme Court did not address this specific question in the Chabot case and so the question remained unanswered. But this was not the end of the case. Five well-known intellectuals (Achterhuis, a philosopher; Koperselman, a psychiatrist; Otten, an author; Goud, a theologian; and Schalken, a lawyer) took issue with the Chabot decision. In their pamphlet *Als de dood voor het leven* (Scared to death of life) they argued that the Supreme Court should have taken a much firmer stand against Chabot's assistance of Mrs.

16 Commissie Aanvaardbaarheid Levensbeëindigend handelen, *Discussienota Hulp bij zelfdoding bij psychiatrische patiënten*, Utrecht, KNMG (1993).

17 Maas, P.J. van der & Wal, G. van der, *Euthanasie en andere medische beslissingen rond het levenseinde. De praktijk en de meldingsprocedure*, Den Haag, SDU (1996) 202-217.

18 Chabot, B.E., *Zelf beschikt*, Amsterdam, Balans (1993).

Boomsma.¹⁹ As a result of the decision by the Court, which was reported and discussed in many articles in newspapers and magazines, and because of this pamphlet, the moral and ethical questions raised by the Chabot case were widely discussed in the Netherlands.

In October 2000 a case before the Haarlem District Court added new elements to the debate. A general practitioner, Sutorius, had chosen to help the former senator Brongersma to take his own life. Brongersma suffered from some problems of old age, such as difficulty with walking. However, apparently his main reason for wanting to die was that life had ceased to have meaning in his eyes. Being 86 years of age, he had been retired from work for some time. He felt alienated from modern life when he read his daily newspaper. All his friends had died. He was lonely and weary of life – he felt as if death had forgotten to fetch him.²⁰ Prof. De Beaufort, a well-known medical ethicist and expert witness, testified that there was no consensus in medical ethics as to what does and does not constitute unbearable suffering. However, in her personal opinion one should adopt a broad definition of this concept. Given such a broad definition it might very well have been the case that Mr. Brongersma had indeed suffered unbearably. The Court of Law sided with De Beaufort's vision and Sutorius was acquitted.²¹ The prosecution decided to appeal.

Like the Chabot case, the Brongersma verdict was widely discussed among experts and in the media. And as it happened, the verdict in the Brongersma case was rendered on the same day that the new law on euthanasia was discussed in a parliamentary committee meeting.²² As might have been expected cabinet members and members of parliament were asked for their opinion on the verdict and felt obligated to take a stand on the Brongersma case. The euthanasia bill was supposed to regulate euthanasia for patients who are suffering unbearably and without any prospect of improvement, but did this include psychiatric suffering? And did it include unhappiness, loneliness, and other forms of discontent without a specific medical cause? During the debate in the Second Chamber (*Tweede Kamer*, i.e. the Dutch lower house) opinions seemed to differ. The Minister of Justice, Korthals (Liberal Party, VVD), argued that the bill was certainly not meant to cover cases in which the individual requesting euthanasia was 'merely' tired of life.²³ The Minister for Health, Borst (Democrats '66, D66), on the other hand, argued that she did not know whether patients who felt tired of life were really not suffering from a disease

19 Achterhuis H., et al., *Als de dood voor het leven. Over professionele hulp bij zelfmoord*, Amsterdam, G.A. van Oorschot (1995).

20 Pans, E., *Klaar met leven. Hulp bij zelfdoding aan hoogbejaarden*, unpublished manuscript, University of Amsterdam (2000), 43.

21 Rechtbank Haarlem, ELRO nummer AA7926, Zaaknr. 15/035127-99 (www.rechtspraak.nl). The Amsterdam Court of Appeal found Sutorius guilty in december 2001. Sutorius now awaits a Supreme Court verdict

22 TK 26691, nr. 22, 33.

23 TK 26691, nr. 22, 60.

after all.²⁴ A few smaller parliamentary groups (the GreenLeft party and her own social-liberal D66) sided with Minister Borst. Other parliamentary party groups seemed to choose Korthals' position.

When the bill subsequently was discussed in the First Chamber (*Eerste Kamer*, i.e. the Dutch senate) Korthals' position prevailed. The cabinet argued time and again that the criterion of unbearable suffering would lose its bite and meaning if it were extended beyond the context of illness and disease. Doctors were not supposed to judge on matters outside their field of expertise.²⁵ So apparently the legislature has drawn the line between acceptable and unacceptable euthanasia as follows: In order to make a legitimate request for euthanasia or medical assistance in suicide one should suffer from a medical condition, 'preferably' a physical ailment. In exceptional cases a request might relate to psychiatric disease, but in those cases the physician should proceed with extreme care.²⁶ Despair, loneliness, or unhappiness, however, do not as such qualify as legitimate grounds for euthanasia.

As stated earlier with regard to psychiatric illness, the Royal Dutch Medical Association (KNMG) agreed with the Supreme Court's verdict in the Chabot case: in exceptional cases euthanasia or physician-assisted death should be available for psychiatric patients, provided the psychiatrist proceeds with extraordinary care. Until now the Association has not taken a stand on cases like the one that doctor Sutorius was asked to deal with. The KNMG recently installed a committee to reflect on the Brongersma case, but this committee has not yet published a report.²⁷ Scarce statements in the past suggest that the doctors' association would not be very keen on having their territory expanded so as to include all kinds of unhappiness and misfortune.²⁸ Empirical research among doctors has shown that as a rule they do not tend to comply with a request for euthanasia from patients who do not suffer from one or another medical condition.²⁹ This would suggest that doctors support the line drawn by the legislature, i.e. the position taken by Minister Korthals in particular.

How does this line between acceptable and unacceptable cases of euthanasia, as drawn by the politicians, relate to the line or lines drawn by ordinary citizens? Do they agree with Minister Korthals' position? Or does public opinion support the position taken by Minister Borst? This is what we have tried to determine on the basis of our surveys of 1995 and 2001. We presented our respondents with the sad story of Mrs. Langezaal, a woman suffering from a psy-

24 TK 26691, nr. 22, 76.

25 EK 26691, nr. 137b, 32, 34, 42.

26 TK 26691, nr. 6, 60, EK 26691, nr. 137b, 36.

27 Th.M.G. van Berkestijn, a well-known doctor, wrote in a newspaper article that many doctors do not want to have the criterion of unbearable suffering expanded ever further by law-courts. Th.M.G. van Berkestijn, 'Ondraaglijk lijden is niet wettelijk vast te leggen', *de Volkskrant*, 24-4-2001, 7.

28 Weyers, H., unpublished manuscript.

29 Haverkate, I., *et al.*, 'Weigering van verzoeken om euthanasie of hulp bij zelfdoding meestal gebaseerd op ingeschatte niet-ondraaglijkheid van het lijden', (2001) 145 *Nederlands Tijdschrift voor Geneeskunde*, 80-84.

chiatric disease. This case of Mrs. Langezaal (see Table 3 for the question wording and results) was included in both surveys, so we can compare the opinions of 1995 and 2001.

Mrs. Langezaal:

Mrs. Langezaal is a middle-aged woman. She is *physically* in sound health, but not *mentally*. She has suffered for years from depression and the treatment provided by the doctor has not helped. She repeatedly tells her doctors that she wishes to die. She has also once attempted to commit suicide, but was unsuccessful. Mrs. Langezaal goes to her psychiatrist and requests a potion with which she can end her life. The psychiatrist provides her with this potion.

**Table 3. Opinions towards euthanasia.
The case of Mrs. Langezaal, 1995 and 2001**

<i>Question:</i>		
Could you indicate what your reaction is to the action of the psychiatrist?		
a. It was correct of the psychiatrist to provide the potion, because the woman had repeatedly indicated her wish to die.		
	1995	2001
[completely] disagree	46%	48%
4	11	8
[completely] agree	31	27
don't know/no answer	12	18
total	100%	101%
N=	911	991
b. It was not correct of the psychiatrist to provide the potion, since patients suffering from mental illness can recover.		
	1995	2001
[completely] disagree	26%	26%
4	12	13
[completely] agree	42	43
don't know/no answer	19	19
total	99%	101%
N=	911	991
c. It was not correct of the psychiatrist to provide the potion, since patients suffering from mental illness are not able to make decisions about their own life and death.		
	1995	2001
[completely] disagree	30%	30
4	11	12
[completely] agree	40	39
don't know/no answer	19	19
total	100%	100%
N=	911	991

Note: differences for 1995 and 2001 are statistically significant (at .01) for statement a and not for b and c.

Apparently, opinions diverged in 1995 and still differ in very much the same way in 2001 on whether euthanasia or assistance to suicide to psychiatric pa-

tients should be permitted.³⁰ In both years a plurality, and even a majority if we exclude the respondents who did not give an answer to this question, disagreed with the statement that the psychiatrist had acted correctly (Table 3; statement a). In both years some 30 percent of our respondents agreed with the action of the psychiatrist. An important reason for rejection of his action seems to be that many people think that patients suffering from a mental illness still have the chance to recover from their illness (Table 3; statement b). A large minority of 42 percent of the respondents (i.e. a majority of the respondents who answered the question) agreed with a statement with this meaning, as against 26 percent who disagreed. There is also a plurality of respondents who agreed with the statement that the psychiatrist acted wrongly since patients like Mrs. Langezaal, suffering from a mental illness, are not able to decide over their own life and death (Table 3; statement c).

We see that in the case of mentally ill patients as Mrs. Langezaal public opinion is strongly divided. Most people have reservations concerning euthanasia in this situation, but a substantial minority of about 25 to 30 percent seems ready to accept physician-assisted death even in the case of mental illness.

3.3 *Unhappiness and despair*

Some 'patients' may not be patients at all, but still they suffer unbearably and want to put an end to their sufferings. What about euthanasia in this kind of cases? How would the public feel about the Chabot case if the Court of Law had followed Chabot's own evaluation that Mrs. Boomsma did *not* suffer from a psychiatric disease? To probe for opinions with regard to euthanasia under these specific circumstances, we presented our respondents with the tragic life of Mr. Van der Helm (see Table 4). This was a new case added to the questionnaire in 2001, so we cannot compare the results of 2001 with opinions from 1995.

Most respondents seem to think that euthanasia and medically assisted suicide is not intended to end the lives of unfortunate people like Mr. Van der Helm. A large majority of all respondents (72 percent) disagreed with the fact that his doctor had given Mr. Van der Helm the pills since he was so extremely unhappy, and only a small minority of 6 percent agreed (Table 4; statement a). Of the respondents who responded to this particular statement – almost 20 percent did not – almost 90 percent disagreed and less than 10 percent agreed with this action of the doctor. The fact that Van der Helm compellingly asked his doctor for the pills is clearly not sufficient reason to create support for or acceptance of the action of the doctor. A majority of 70 percent of our respon-

30 Only for the first statement (a) there is a statistically significant (but small) difference between opinions in 1995 and 2001, most likely due to the fact that in 2001 more respondents did not know the answer or did not want to give an answer to this question. For the other two statements there was no statistically significant difference (at .01) between 1995 and 2001.

dents disagreed with the statement that it was correct for the doctor to provide the pills, although Mr. Van der Helm had pleaded for them (Table 4; statement b). Less than 10 percent agreed with this statement, while almost 20 percent did not have an opinion or gave none.

Mr. Van der Helm:

Mr. Van der Helm is 55 years old. His only son died four years ago in a traffic accident. After the death of his son, his marriage deteriorated. He is now divorced from his wife. Mr. Van der Helm no longer enjoys his work. He is extremely unhappy and has repeatedly asked his family physician if he would help him to end his life. The family doctor finally decides to give Mr. Van der Helm the pills that will allow him to carry out his wish.

**Table 4. Opinions towards euthanasia.
The case of Mr. Van der Helm, 2001**

<i>Question:</i>	
Could you indicate what you think about the action of the doctor?	
a. It was correct of the doctor to provide the pills, because Mr. Van der Helm was extremely unhappy.	
	2001
[completely] disagree	72%
4	3
[completely] agree	6
don't know/no answer	19
total	100%
N=	991
b. It was correct of the doctor to provide the pills, because Mr. Van der Helm pleaded for them.	
[completely] disagree	70%
4	3
[completely] agree	8
don't know/no answer	18
total	99%
N=	991
c. It was not correct of the doctor to provide the pills, because Mr. Van der Helm is not in fact ill.	
[completely] disagree	16%
4	4
[completely] agree	70
don't know/no answer	10
total	100%
N=	991

The lack of support for the doctor in this case seems to be the result of the idea that Mr. Van der Helm was not 'really' ill. Seven out of every ten respondents in our survey agreed with the statement that he acted incorrectly, since Mr. Van der Helm was not in fact ill, and less than one out of seven disagreed (Table 4; statement c). He may be extremely unhappy, but apparently this was not the same as a physical or mental illness and as a consequence it is not an acceptable ground for euthanasia. Evidently only in the case of a serious and real

illness is there acceptance of or support for a doctor helping someone to end his or her life.

If the conclusion based on the case of Mr. Van der Helm is correct, one would expect that people would disapprove even more strongly if one were to consider medical assistance to suicide for people who are neither ill nor as desperately unhappy as Mr. Van der Helm was. We presented our respondents in 2001 – this also is a new case, so we do not have comparable data from 1995 – a vignette inspired by the assisted suicide of senator Brongersma. In the sketch in our questionnaire we renamed him Mr. De Bruyn (see Table 5 for the question wording and results).

If the doctor had behaved as public opinion suggests Mr. De Bruyn would probably have lived for some more years, lonely and unhappy as he might have been. Two out of every three respondents in our 2001 survey agree with the statement that, because he is not sick, the doctor should not provide De Bruyn with the potion with which he could commit suicide; less than one out of five disagrees (Table 5; statement a). The fact that De Bruyn himself requested this potion does not really change the evaluation of this case: 60 percent of our respondents disagree with this procedure, while 14 percent agree and almost 20 percent do not know or do not want to give an opinion (Table 5; statement b).

People may perhaps feel sorry for the loneliness and unhappiness of Mr. De Bruyn, but this surely is not a sufficient reason for the doctor to give him a lethal potion. Almost 80 percent of the respondents who gave an answer to this question, i.e. 63 percent of all respondents (Table 5; statement c), disagree with the statement in which it is said that the doctor should provide De Bruyn with the potion since he is so lonely and unhappy. For fewer than 15 percent the fact that he is lonely and unhappy is reason enough to accept the action of the doctor of Mr. De Bruyn.

The answers to the questions with regard to the cases of Mr. Van der Helm and Mr. De Bruyn suggest that the public supports the line between acceptable and unacceptable euthanasia as drawn by the legislature in general and Minister Korthals in particular. Euthanasia and medically assisted suicide is some sort of ‘privilege’ for patients suffering unbearably from a medical condition. Apparently, according to Dutch citizens, doctors are not supposed to solve non-medical problems by means of lethal potions for unhappy, lonely or otherwise weary people. One might rightly wonder what exactly makes people support this legal boundary then. Do they object to the idea that doctors would operate outside their field of expertise if they were to help people who do not qualify as patients? Or do they object to the mere fact that these unhappy people should have access to an easy death? We can address these questions on the basis of a euthanasia-related topic, i.e. the so-called Drion pill.

Mr. De Bruyn:

Mr. De Bruyn is 86 years of age. He was a professor at the university. He then enjoyed his life. Now he is old and many of his friends are dead. He never married and has no children. He often feels lonely, but he is not sick and he is also mentally alert. Mr. De Bruyn could live many more years. But De Bruyn does not look forward to this pros-

pect. He would rather die. He has told this many times to his family doctor. Mr. De Bruyn requests a potion from his doctor with which he can end his life. The doctor is uncertain concerning what action he should take.
What do you think? Could you answer this by giving your response to the following statements?

**Table 5. Opinions towards euthanasia.
The case of Mr. De Bruyn, 2001**

<i>Question:</i>	
Could you indicate what you think about the action of the doctor?	
a. The doctor should not provide the potion, because Mr. De Bruyn is not sick.	
	2001
[completely] disagree	18%
4	5
[completely] agree	66
don't know/no answer	10
total	99%
N=	991
b. The doctor should provide the potion, because Mr. De Bruyn has pleaded for it.	
[completely] disagree	61%
4	6
[completely] agree	14
don't know/no answer	19
total	100%
N=	991
c. The doctor should provide the potion, because Mr. De Bruyn is lonely and unhappy.	
[completely] disagree	63%
4	5
[completely] agree	12
don't know/no answer	20
total	99%
N=	991

3.4 The Drion pill

Shortly after the euthanasia law was accepted by the senate the Minister for Health, Mrs. Borst, gave an interview to the *NRC Handelsblad*, a national newspaper. The Minister said that she would be in favor of what the Dutch refer to as the 'Drion pill'. Almost ten years before this interview with Mrs. Borst, in 1991, Drion, a retired member of the Dutch Supreme Court, wrote an article for the same newspaper. He argued that many old people were not ill and thus could not ask for euthanasia. However, in the opinion of Drion some of them would be very happy if they were able to acquire some sort of medication that would enable them to take their own life at a moment of their own choosing. Drion suggested that such medication – ever since referred to as the

Drion pill – could be given to them at their request.³¹ During the interview in April 2001 Minister Borst did not quite embrace this proposal, but she thought it deserved serious consideration and a thorough societal debate.³² The Dutch Association for Voluntary Euthanasia (NVVE) immediately took up this suggestion and proposed a nation-wide discussion on the Drion pill.³³

Introduction of a Drion pill would give an individual the opportunity of ending his or her own life without any further medical help or assistance. So if people do not want doctors to step outside their field of expertise, providing a Drion pill might be an alternative for people like Mrs. Boomsma and senator Brongersma. We asked our respondents in 1995 and 2001 questions on the Drion pill (see Table 6 for question wording and results) to determine what Dutch citizens think of this possibility.

There is no widespread support for the Drion pill as we sketched this option in our questionnaire. A minority of some 30 percent of our respondents agrees with a proposal to this effect, but more (over 40 percent) disagree (Table 6; statement a). This is equally true for 1995 and 2001.³⁴ However, it is interesting to see that the disapproval of assistance in suicide for Mr. Van der Helm and Mr. De Bruyn is larger than the disapproval of the Drion pill. The proportion of respondents who disagreed with the doctors helping Mr. Van der Helm and Mr. De Bruyn was much more substantial.

The fear of misuse of the Drion pill seems to be an especially important reason for rejecting the proposal. In both our surveys half of all respondents agreed with the statement that the Drion pill may be a good proposal as such, but that it is not a good idea to put it in practice since the danger of misuse is too great. For every advocate there are two opponents (Table 6; statement b). The fact that elderly people might feel expendable if the Drion pill were made available may be relevant as well: almost half of the respondents who answered this question thought it a bad proposal because elderly people might be made to feel expendable and redundant (Table 6; statement c).

Advance Directives:

Elderly people sometimes fear the future. They are afraid of becoming invalids or demented. They are also afraid they will lose their dignity at the end of their lives. They do not wish to be placed in an institution in such a condition. It has been suggested that such persons should be provided with the possibility of deciding for themselves to terminate their life. For example,

31 See for the original article *NRC Handelsblad*, 19-10-1991. Drion's article was reprinted in Drion, H., *Het zelfgewilde einde van oude mensen*. Met reacties van Ch. J. Enschedé, H. Kuiter en anderen, Amsterdam, Balans (1992).

32 Oostveen, M., 'Minister Els Borst over het tekort van de nieuwe euthanasiewet', in: *NRC Handelsblad*, 14-4-2001; Borst's interview was subsequently discussed in parliament, HTK 19-4-2001, 70-4644-4667.

33 'Nu zelfdoding ter discussie. Vereniging voor vrijwillige euthanasie begint debat over de pil van Drion', in: *Trouw*, 17-5-2001.

34 For all three statements on the Drion pill presented there are no statistically significant differences (at .01) between 1995 and 2001.

they might request a potion or a pill from their doctor. Then they could decide for themselves at what moment they would die.

Table 6. Opinions towards euthanasia: the so-called Drion pill, 1995 and 2001

Question:

What is your opinion concerning this proposal?

a. It is a good proposal, because elderly people must have the right to terminate their lives when they wish.

	1995	2001
[completely] disagree	44%	43%
4	9	11
[completely] agree	33	29
don't know/no answer	14	17
total	100%	100%
N=	911	991

b. It is a good proposal, but it should not be put in practice because of the great danger for misuse.

[completely] disagree	26%	23%
4	9	9
[completely] agree	50	51
don't know/no answer	15	18
total	100%	100%
N=	911	991

c. It is a bad proposal, because elderly persons can thereby feel expendable.

[completely] disagree	33%	28%
4	7	8
[completely] agree	42	42
don't know/no answer	18	22
total	100%	100%
N=	911	991

Note: differences for 1995 and 2001 are not statistically significant (at .01) for statement a, b and c.

Hence it does not seem likely that they would be very much in favor of a self-help route to death instead of medically assisted suicide or euthanasia. There may be some support for the idea in general, but according to a majority or at least a plurality of Dutch citizens the potential dangers and negative side effects of a Drion pill in one form or another are too great.

3.5 Advance directives

The Chabot-Brongersma line between acceptable and unacceptable euthanasia is not the only limitation introduced in the new Dutch law on euthanasia. An-

other topic that was debated was the status of advance directives (or living wills) drawn up by patients before they became senile, most often due to Alzheimer's disease. Partly as a result of years of campaigning, information and guidance by the Dutch Society for Voluntary Euthanasia (NVVE), many Dutch citizens carry an advance directive. In these documents many of them indicate they do not want to be treated – or even want their lives terminated – should they ever reach a state of Alzheimer's disease in which they, for example, are no longer able to recognize their loved ones. But should doctors honor these requests, and if so, in what way? During the parliamentary debate about the new euthanasia law it became clear that doctors can end the life of demented patients on the basis of an advance directive. However, this directive can only be carried out if the doctors are convinced that the other criterion in the law has been fulfilled: the patient involved must be suffering unbearably. Doctors are not supposed to terminate the lives of senile people on the basis of an advance directive alone. Again: How about public opinion in the Netherlands? Do ordinary Dutch citizens think that demented people may be 'killed' on the basis of an advanced directive they wrote when they were still competent?

In order to gauge public opinion on this question, we presented our respondents with the case of Mrs. Hendriks. We presented this case of Mrs. Hendriks in 1995 as well as in 2001, but we changed the presentation and the formulation of the situation in our 2001 survey. This makes it difficult or even impossible to compare the results.³⁵ In Table 7 the questions and results for both years are included.

The presence of an advance directive or at least a written request is important in evaluating various cases of euthanasia. This is what we conclude when we compare the reactions to the first statement (a) of 1995 and 2001. In the situation we sketched in 1995 Mrs. Hendriks did not have a written request, in the situation of 2001 she explicitly did. In 1995 40 percent was in agreement with the statement that it was quite acceptable for the doctor to give her the lethal injection because it was her own wish, whereas in 2001 a large majority of 69 percent agreed with this statement. Although in 2001 we changed the situation of Mrs. Hendriks on more than this point, the fact that she had drawn up a written request before she became demented is the most plausible reason for this statistically significant and substantial increase of support for the action of the doctor. We may find some support for this interpretation in the responses to a question we asked only in 1995 (Table 7; statement b). In that year half of the respondents thought it acceptable to give the injection, but only if Mrs. Hendriks repeatedly had made her request before she became demented. Also the reaction to the fourth statement (Table 7; statement c) – an identical statement for 1995 and 2001, but set in a different context – appears to support the idea that a request made when one was still mentally healthy is relevant for the evaluation of the behavior of the doctor. In 2001 more people

35 This may explain that in this case the opinions in reaction to statements a and c are statistically significant (at .01) for 1995 and 2001; there is no difference for statement d.

disagree with the statement that the injection should not be allowed, because Mrs. Hendriks is demented and not able to decide what she wishes – in 2001 her request is in accordance with her wish ten years earlier, when she was still of sound mind.

So in the case of Mrs. Hendriks the presence of an explicit request, made when she was not yet mentally affected or ill, appears to be of critical importance. It is not the fact that she is not physically ill but ‘only’ demented that is most relevant, as we can see in the reactions to the last statement of this case (Table 7; statement d). Here we see that both in 1995 and in 2001 a majority of the respondents was in disagreement with the idea that it is not acceptable for the doctor to give her the injection, because she is not suffering any physical pain. It is interesting to note that the support for euthanasia in the case of a demented patient carrying an advance directive or living will, is greater than the support for physician-assisted suicide in the case of psychiatric patients and old people longing for death, even though these last categories might be able to describe their sufferings much better and thus convince their doctors that their suffering is indeed unbearable. Perhaps Dutch citizens assume that Alzheimer’s disease implies unbearable suffering. Or perhaps they know that as yet there is no prospect of improvement for people suffering from Alzheimer’s disease. After all, one of the arguments leading to reservation in the case of Mrs. Langezaal was the thought that patients suffering from a mental illness can recover.

Mrs. Hendriks 1995:

Some elderly persons get demented. Mrs. Hendriks is such a person. She is 79 years old and has lived for several years in a care center. She is severely demented. She no longer recognizes her daughter. She is quite confused and no longer trusts anyone. She is afraid of other people and she behaves badly.

Mrs. Hendriks has repeatedly told her daughter that she would rather be dead. She has also told the doctor and nurses of the care center that she no longer wishes to live. She wants an injection, so she has said. The doctor finds it a difficult question and does not know what to do.

Mrs. Hendriks 2001:

Some elderly persons get demented. Mrs. Hendriks is such a person. She is 79 years old and has lived for several years in a care center. She is severely demented. She no longer recognizes her daughter. Ten years ago, before she got in this condition, Mrs. Hendriks signed a statement in which she declared that if she were to become demented, she wanted her physician to give her an injection. The daughter of Mrs. Hendriks now feels that the physician should carry out this wish. The physician has doubts and is uncertain what to do.

Table 7. Opinions towards euthanasia.
The case of Mrs. Hendriks, 1995 and 2001

<i>Question:</i>			
What do you think?		1995	2001
a)			
It is acceptable for the doctor to give her the injection, because it was after all her wish			It is acceptable for the doctor to give Mrs. Hendriks the injection, because that was her wish
[completely] disagree (1,2,3)	35%	16%	[completely] disagree (1,2,3)
(4)	10%	5%	(4)
[completely] agree (5,6,7)	40%	69%	[completely] agree (5,6,7)
don't know	15%	10%	don't know
total	100%	100%	total
N	911	991	N
b)			
It is acceptable for the doctor to give her the injection, but only if Mrs. Hendriks repeatedly had made her request before she became demented			
disagree (1,2,3)	27%		
(4)	8%		
agree (5,6,7)	50%		
don't know	15%		
total	100%		
N	911		
c)			
It is not acceptable for the doctor to give her the injection, because Mrs. Hendriks is demented and thus not able to decide what she wishes			It is not acceptable for the doctor to give her the injection, because Mrs. Hendriks is demented and thus not able to decide what she wishes
disagree (1,2,3)	35%	58%	disagree (1,2,3)
(4)	10%	6%	(4)
agree (5,6,7)	34%	14%	agree (5,6,7)
don't know	20%	22%	don't know
total	100%	100%	total
N	911	991	N
d)			
It is not acceptable for the doctor to give her the injection, because Mrs. Hendriks is not suffering any physical pain			It is not acceptable for the doctor to give her the injection, because Mrs. Hendriks is not suffering any physical pain
disagree (1,2,3)	52%	56%	disagree (1,2,3)
(4)	8%	7%	(4)
agree (5,6,7)	19%	18%	agree (5,6,7)
don't know	22%	20%	don't know
total	101%	101%	total
N	911	991	N

Note: differences for 1995 and 2001 are statistically significant (at .01) for a and c, not for d.

4. Conclusion

The new Dutch law on euthanasia and medical assistance to suicide establishes two important criteria for euthanasia. The patient must have made a voluntary and well-considered request and he or she must suffer unbearably without any prospect of improvement. During the parliamentary proceedings the government clarified both criteria. In this article we tried to find out whether public opinion coincides with the government's interpretation of these criteria.

According to the government a voluntary and lasting request might also take the form of an advance directive written before the patient became ill and mentally incompetent. Public opinion in the Netherlands supports this position. A majority of respondents in our survey tends to think that euthanasia for Alzheimer patients on the basis of an advance directive is acceptable. According to the Dutch medical profession and – following their lead – according to Dutch politicians, in exceptional cases psychiatric patients will be able to make a voluntary and lasting request for medical assistance in suicide or physician-assisted death. If these patients suffer from a hopeless condition, their request may be honored. This cautious position seems to be supported by ordinary Dutch citizens as well. Opinions suggest a hovering balance between proponents and opponents of assistance in suicide for psychiatric patients who are incurably ill.

According to the Dutch government the legal criterion of unbearable suffering should be situated in a medical context, i.e. an individual must suffer from a medical condition in order to make medical help in dying 'legally acceptable'. Despair and unhappiness do not qualify as medical conditions. Hence, according to the government, people who are old and tired of life should not be eligible for lawful medical assistance in suicide. Again the government's position seems to be in almost complete agreement with public opinion. Our respondents disapproved of medical help in dying for unhappy people or elderly people who feel that their lives are over. There also does not seem to be much enthusiasm for a self-help suicide pill that would allow people to take their own lives in a decent way, but without medical assistance. Generally speaking, our respondents seem to have many doubts about the feasibility and the practical consequences of such a suicide pill.

The new so-called euthanasia law was widely criticized, inside the Netherlands but especially abroad. The new law and the accompanying parliamentary proceedings introduce substantive criteria for lawful euthanasia. On the basis of our survey we are tempted to conclude that the legislation as it has been accepted in parliament and in particular as interpreted by government enjoys broad support among ordinary Dutch citizens. For democrats who appreciate the principle that people want to live under a legal regime whose contents they value, this may be a reason to soften the criticism on the Dutch euthanasia policy.

End-of-life Decisions in Six European Countries

A research note

Agnes van der Heide, Bregje Onwuteaka-Philipsen,
Paul J. van der Maas, Gerrit van der Wal

1. Introduction

Until recently, death was regarded as the ultimate defeat of medicine. Curing disease and prolonging life have traditionally been the main goals of health care, but physicians have now become aware of their responsibility beyond the stage at which death is inevitable and recognise adequate care for the terminally ill as another important goal of medicine. Several medical, epidemiological, demographical and cultural factors have contributed to the current interest for death and dying and for palliative care and medical decision-making for terminally ill patients. Advances in medical technology have strongly increased the ability of medicine to prolong the life of seriously ill patients. These developments inevitably yield questions about whether applying such technology is appropriate and beneficial to the patient in all cases. Furthermore, cancer is an increasingly important cause of death, because of decreasing death rates from cardiovascular disease. Cancer has been shown to be a cause of death that frequently concurs with end-of-life decision-making, because it relatively often involves a non-sudden and sometimes protracted dying process. One of the most important current demographical developments is the ageing of the population. Death now mainly occurs at old age and death rates per 1000 inhabitants are rising because of the absolute and relative increase in the number of elderly patients. Finally, in modern society there seems to be an increasing emphasis on patient autonomy. People want to control their own life including the end of it, and they want to have a voice in how and when they die.

Medical care at the end of life is aimed at improving the quality of the last or terminal stage in life and as such, involve consideration of medical practices that, intentionally or unintentionally, may shorten the remaining life span or hasten the moment of dying. Such medical decisions at the end of life, or end-of-life decisions, include:

1. decisions about whether or not to *withdraw or withhold* potentially life-prolonging treatment, e.g. mechanical ventilation, tube-feeding, dialysis;
2. *alleviation of pain or other symptoms* with, e.g., opioids, benzodiazepines or barbiturates, in dosages large enough to hasten death as a possible or certain side effect;

3. *physician-assisted death*, including *euthanasia* and *physician-assisted suicide*, which are defined respectively, as the administration of drugs with the explicit intention of ending the patient's life at the patient's explicit request, and the prescription or supply of drugs with the explicit intention of enabling the patient to end his or her own life, physician-assisted death has been shown to occur without the patient explicitly asking for it in a small number of cases, too.

2. Empirical Research on End-of-Life Decision Making

Medical end-of-life decisions may occur in any medical setting where patients die, i.e., in hospitals, in nursing homes, and at home, where the general practitioner is often the attending physician. End-of-life decisions represent an important area of medical decision-making that is closely related to other professional domains because of its legal, ethical and societal aspects. The issue is and has been broadly and sometimes vehemently discussed in society and in science. Euthanasia, for example, stands among a core of subjects that have aroused controversy through the ages. The circumstances of societies differ, but the arguments roughly remain the same. Data from empirical and observational research on the occurrence and backgrounds of end-of-life decision-making have been introduced into the debate relatively recently. Ethical as well as legal and political reasoning can to a great extent benefit from empirical and observational data on epidemiological knowledge, such as the prevalence of end-of-life decisions and the clinical characteristics of the patients involved. This also holds for opinion and attitude surveys among physicians, nurses, patients and the general population on a variety of aspects of end-of-life decision-making.

A number of empirical studies on the prevalence and backgrounds of these end-of-life decisions have been described in the medical literature. The Dutch landmark studies on euthanasia and other end-of-life decisions have been the first to show that hastening death is an important issue in end-of-life care.¹ In the Netherlands, 43% of all deaths were shown to have been preceded by medical decisions that probably hastened the end of life in 1995. Thus far, Belgium and Australia are the only countries in which comparable studies have been done and these yielded similar figures.² End-of-life decisions most frequently and increasingly concern withholding or not starting potentially life-

1 Maas, P.J. van der, *et al.*, 'Euthanasia and other medical decisions concerning the end of life', (1991) 338 *Lancet*, 669-674; Maas, P.J. van der, *et al.*, 'Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990-1995', (1996) 335 *New England Journal of Medicine*, 1699-1705.

2 Deliens, L., *et al.*, 'End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey', (2000) 356 *The Lancet*, 1806; Kuhse H., *et al.*, 'End-of-life decisions in Australian medical practice', (1997) 166 *Medical Journal of Australia*, 191-196.

sustaining interventions, which precede death in 20% of all cases in the Netherlands.³ The management of pain and other symptoms in the last stage of life has improved considerably during the last one or two decades, but large dosages of opioids or comparable drugs had the possible side effect of hastening death in 19% of all deaths. Administration of drugs to deliberately end life occurs in about 3% of all deaths: death is the result of euthanasia in 2.4% of all deaths, of physician-assisted suicide in 0.2%, and of the ending of life without the patient having explicitly asked for it in 0.7%.⁴ Decisions to withhold or withdraw life-sustaining treatment have also been studied relatively frequently in the U.S., showing that in the U.S. over 75% of patients die after forgoing treatment.⁵

Whereas epidemiological research concerning medical decision-making at the end of life is thus rather scarce, attitudes among medical professionals towards euthanasia, assisted suicide and non-treatment decisions have been studied more widely. In Europe, studies have been carried out in Denmark, Germany, Italy, the Netherlands, Norway, Sweden, and the United Kingdom.⁶ One third of Danish physicians were found to think it ethically acceptable to give a terminal cancer patient a lethal injection on request and 29% would find the practice acceptable if it were legal. In Sweden, between 13 and 34 % of different groups of physicians believe that euthanasia should be legalised; between 37 and 67 % are opposed to any change of the law, and between 18 and 34 % answer that they feel uncertain. In Norway, 17% of physicians think they should be permitted to bring the life of a terminal ill patient to an end if the patient asks for it. Of Dutch physicians, 12% would never perform euthanasia or physician-assisted suicide. In Germany, most physicians strongly oppose euthanasia (in the sense of active assistance to die at the patient's request) and

3 Groenewoud, J.H., *et al.*, 'A nationwide study of decisions to forego life-prolonging treatment in Dutch medical practice', (2000) *Archives of Internal Medicine*, 160, 357-363.

4 Maas, P.J. van der, *et al.*, 'Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990-1995', above, 1699-1705.

5 Faber-Langendoen, K., 'A multi-institutional study of care given to patients dying in hospitals: ethical and practice implications', (1996) *Archives of Internal Medicine*, 156, 2130-2136; Prendergast, T.J., *et al.*, 'A national survey of end-of-life care for critically ill patients', (1998) *American Journal of Respiratory and Critical Care Medicine*, 158, 1163-1167.

6 See, for example, Folker, A.P., *et al.*, 'Experiences and attitudes towards end-of-life decisions amongst Danish physicians', (1996) *Bioethics*, 10, 233-249; Sjøkvist, P., *et al.*, 'Withdrawal of life support – who should decide? Differences in attitudes among the general public, nurses and physicians', (1999) *Intensive Care Medicine*, 25, 949-954; Nilstun, T., *et al.*, (1996) 'Disagreement among physicians about active euthanasia. 245 answers from a Swedish questionnaire reflect uncertainty', *Läkartidningen*, 93, 1350-1351; Forde, R., *et al.*, 'The ethics of euthanasia – attitudes and practice among Norwegian physicians', (1997) *Social Science and Medicine*, 45, 887-892; Wehkamp, K.-H., *Sterben und Töten. Euthanasie aus der Sicht deutscher Ärztinnen und Ärzte. Berliner Medizinethische Schriften*, Berlin, Humanitas Verlag (1998); Di Mola, G., *et al.*, 'Attitudes toward euthanasia of physician members of the Italian Society for Palliative Care', (1996) *Annals of Oncology*, 7, 907-911; Wal, G. van der, Maas, P.J. van der, *Euthanasia and other medical decisions concerning the end of life. Practice and notification procedure*, The Hague, Sdu Publishers (1996); Shah, N., *et al.*, 'National survey of UK psychiatrists' attitudes to euthanasia', (1998) *The Lancet*, 352, 1360.

simultaneously give strong support to 'indirect euthanasia', that is, using potentially lethal dosages of opioids. In Italy, where there is an important influence of the Catholic Church, the issue of euthanasia is very controversial and end-of-life decision-making is especially debated in the context of palliative care approaches for terminally ill patients.

3. International Comparison

The significance and meaning of a study on end-of-life decision-making in one single country is limited.⁷ The organisation and accessibility of the health care system, the legal system, cultural and historical aspects, as well as epidemiological factors all have to be considered while trying to understand and interpret epidemiological and clinical findings on the prevalence and backgrounds of end-of-life decision-making, and opinions and moral judgements towards this subject. Furthermore, whereas actual practices cannot be compared due to the lack of studies in most countries, international comparison of previous studies on attitudes and medical practices concerning the end of life is also rather difficult, because of differences in the study designs and in the concepts and definitions used. For instance, is 'bringing the patients' life to end' (Norway) similar to 'prescribing or administering a lethal dose of drugs with the intention to end the patient's life' (wording used in the Netherlands and Belgium), or does it also include alleviation of pain or other symptoms with large dosages of opioids with a probable life-shortening effect (similar to indirect euthanasia in Germany). Therefore, it is to a large extent unknown to what degree practices and opinions and moral judgements in the field of medical decision-making at the end of life vary in Europe.

In order to be able to compare and understand the main features of practices concerning end-of-life decision-making and to evaluate opinions and moral judgements of physicians in different European countries, we have set up an international comparative study in 6 European countries. This project is funded by the European Commission under the fifth framework program. It is aimed at assessing in the 6 participating countries (Sweden, Denmark, the Netherlands, Belgium, Switzerland and Italy) the prevalence and main background characteristics of end-of-life decisions; attitudes concerning end-of-life decision-making among physicians; and differences and similarities in the health care system and in cultural, historical, socio-economical, epidemiological, legal characteristics that may be related to practices and attitudes in the field of end-of-life decision-making.

7 Nilstun, T., *et al.*, 'Surveys on attitudes to active euthanasia and the difficulty of drawing normative conclusions', (2000) *Scandinavian Journal of Public Health*, 28, 111-116.

Medical end-of-life decisions will be understood from a number of perspectives, as was previously done in the Dutch studies. It is important to know a) what a physician actually does or omits to do; b) what the intention in doing so is; c) whether the decision to do so is made at the request of the patient, with informed consent of the patient or after discussion with the patient; d) whether the patient is competent, i.e., able to assess the situation and to make a decision about it adequately. The main hypotheses to be studied are:

1. the variation in frequency and main characteristics of medical decisions concerning the end of life is limited for most countries within Western Europe, provided that the instruments used assess the actual practices in medical care;
2. differences between countries in Western Europe in the frequency and main characteristics of end-of-life decision-making are related to differences in
 - epidemiological characteristics (e.g., the number of deaths due to cancer),
 - demographical characteristics (e.g., differences in the degree of ageing in society),
 - the organisation and accessibility of health care in general and of health care for terminal patients in particular, including the insurance and reimbursement regulations,
 - legal regulations and practices,
 - historical and cultural aspects, such as the extent to which end-of-life decision-making and other medical ethical issues have been or are openly discussed in a country,
 - the extent to which a population is religiously affiliated.

The project consists of two parts that will be conducted simultaneously in the 6 participating countries. The two studies involve:

1. a Death Certificate study; i.e., a *retrospective study* of the prevalence and major characteristics of end-of-life decisions that preceded death in randomised samples of death cases;
2. a Physicians Study, i.e., a *cross-sectional survey* of the practices and attitudes concerning end-of-life decision-making of physicians from specialities in which the death of patients is frequently unavoidable.

The two studies are meant to provide complementary information. Study 1 is aimed at providing a strong quantitative framework of the incidence and main characteristics of end-of-life decisions i.e., decisions about whether or not to withdraw or withhold potentially life-prolonging treatment, decisions on alleviation of pain or other symptoms with drugs in dosages large enough to hasten death and decisions on physician-assisted death. Study 2 is mainly aimed at

giving insight into the attitudes of physicians towards end-of-life decision-making.

4. Expected Results

It is expected that the results of this project, the first of which will be available in April 2003, will contribute to a better understanding of medical practices at the end of life and give insight in opinions and moral judgements about this subject among medical professionals. The empirical base of knowledge that will result from the project will help physicians, citizens and public health policy makers in Europe in developing rational, evidence-based policies that are necessary in this difficult but increasingly important area of decision-making.

The quality of the last stage in life should be supported by scientific research on epidemiological and clinical aspects of end-of-life decision-making. Advances in medical technology continuously increase the possibilities to treat seriously ill patients and to postpone death. Physicians, patients, policy makers and others involved in the decision-making for patients with life-threatening diseases are therefore increasingly confronted with difficult situations that require the utmost care with respect to a balanced consideration of all relevant medical, ethical, psychosocial and societal aspects. Evidence-based health care at the end of life can contribute to transparent and rational medical decision-making, which may result in a better quality of care and in an improved quality of the last stage in life. The results of this study will promote the well-informed establishment of practices, guidelines and policies that are tailored to country specific characteristics while aiming at a comparative high level of medical care for terminal patients in each country.

LEGAL PRACTICE

The Effectiveness of Legal Control of Euthanasia

Lessons from Comparative Law

Margaret Otlowski

1. Introduction

There has, for many years, been ongoing debate about the permissibility of euthanasia and the appropriate role for law and policy.¹ This paper examines differing approaches to the legal control of euthanasia in the clinical context. It seeks to compare and contrast the position adopted in common law jurisdictions where euthanasia is prohibited under criminal law, and that in the Netherlands where the practice has gained legal acceptance and more recently has been legalised under certain conditions. Although this paper is primarily concerned with comparing common law jurisdictions with the Netherlands, the policy of prohibition of euthanasia applies in most other jurisdictions around the world. The arguments developed in this paper regarding the effectiveness of a policy of prohibition are therefore of wider relevance, beyond the common law jurisdictions which are the immediate focus of attention.

In undertaking this comparison of differing legal models, the paper seeks to explore the nature and operation of the common law policy of criminal prohibition of euthanasia with a view to determining its effectiveness in practice. Similarly, it seeks to probe the situation in the Netherlands where a more permissive approach has been taken in order to identify what the implications of this are for law and social policy. Where available, empirical evidence will be drawn on from jurisdictions which prohibit euthanasia as well as the Netherlands to give some objective insights into the practical implications of the different approaches to the legal control of euthanasia.

In the light of this comparative analysis, the paper seeks to evaluate the relative effectiveness of the two approaches in achieving legal control of euthanasia. In so doing, the paper also takes the opportunity to assess the validity of the so called 'slippery slope' argument: i.e. the claim that legalisation of

¹ This terminology, adopted in the Netherlands, is used to convey the concept of medically assisted dying in the clinical context, in particular, provision by a doctor of active assistance to die at the patient's request. Although elsewhere, I have used the terminology of 'voluntary euthanasia' to indicate the patient's request, in the interests of consistency with the other papers in this Issue, the simpler terminology of 'euthanasia' will be used for the purposes of this paper to indicate requested euthanasia. The phrase 'termination of life without request' will be used for non-voluntary euthanasia.

euthanasia would lead to a greater incidence of termination of life without request than would be the case if the practice remained illegal.²

The paper suggests that there are valuable lessons to be learnt from comparative law about the effectiveness of legal control of euthanasia. Not only is it patently evident that the common law's policy of strict prohibition does not prevent the occurrence of euthanasia, the operation in practice of such a policy is fraught with difficulty. And whilst one might expect a greater level of protection from risk of abuse in jurisdictions which directly prohibit the practice, the empirical data to date point, perhaps ironically, to the conclusion that the risks of abuse are greater in a climate where euthanasia is prohibited.

The debate about the legal status of euthanasia has been characterised by unrealistic expectations of the law's ability to control the practice. The paper argues that it is a fallacy to equate prohibition with effective control, or conversely, to assume that the absence of prohibition leads to the uncontrolled or uncontrollable practice of euthanasia. In fact, the available evidence points to the contrary, namely that carefully balanced and measured regulation, which has the support of the medical profession, is far more likely to lead to effective control than outright prohibition which is ignored in practice and attracts widespread cynicism.

2. Common Law Jurisdictions: A Policy of Prohibition

2.1 *The law on the books*

Although in general terms, there are variations in the source and content of the criminal law as between common law jurisdictions, there is a considerable degree of consistency on the issue of euthanasia.³ Because euthanasia involves deliberate and intentional killing (albeit in special circumstances), it is unequivocally prohibited under the criminal law of common law jurisdictions including the United Kingdom, the United States, Australia and Canada.⁴ The criminal law treats such conduct as murder. Provided the doctor has intentionally acted in a way to bring about the patient's death, and has in fact caused the pa-

2 See Otłowski, M., *Voluntary Euthanasia and the Common Law*, Oxford, Oxford University Press (1997) (also now published in paperback (2000)), Chapter 4, especially 218- 228 for more in-depth consideration of slippery slope arguments.

3 In some jurisdictions including the United Kingdom and in some US and Australian states, the common law applies with little legislative interference. However, in many jurisdictions, including Canada, most US states, and a number of States and Territories in Australia, the common law has been codified: for detailed coverage, see Otłowski, M., '*Voluntary Euthanasia and the Common Law*', above, Chapter 1.

4 It should be noted that for a short period of time, legislation was in force in the Northern Territory of Australia permitting euthanasia in certain circumstances (*Rights of the Terminally Ill Act 1995* (NT): this legislation was overturned by the Federal Parliament of Australia with the enactment of the *Euthanasia Laws Act 1997* (Cth).

tient to die at that time and in that manner, the doctor will be legally culpable for the patient's death.

Strictly speaking, the criminal law takes no account of the extenuating circumstances usually existing in such situations: that the patient had requested this intervention, the *bona fide* motives of the doctor, or that the patient's condition was terminal. For the purposes of the criminal law, the consent of the victim is no defence, so the fact that the patient had instigated the request would not exculpate the doctor from liability. Equally, evidence of the compassionate motives of the doctor would be irrelevant in establishing criminal liability for murder because the law takes account of intention rather than motive. Further, the fact that the patient was in an advanced terminal state, with death in any event imminent does not prevent liability from arising: acceleration of an inevitable death constitutes murder. In short, no special defences are available at common law, either through precedent or legislation, to protect doctors from avoiding criminal liability in these circumstances.

2.2 The law in practice

Whilst the criminal law's strict prohibition of euthanasia in common law jurisdictions can be stated with some certainty, what is less clear or predictable, is how the law operates in practice. There is, in fact, a wide gulf between the strict legal position in relation to euthanasia and the position in practice, in terms of what doctors actually do and how the law is applied to them in the rare circumstances where their conduct is exposed.

Despite the common law's prohibition of euthanasia and its classification as the most serious crime of murder, some doctors are nevertheless willing to practice it, although rarely do they come to the attention of the prosecuting authorities. Given the presently illegal nature of these activities, there are inevitably difficulties in ascertaining the exact extent of these practices. Nevertheless, anonymous surveys of doctors, professionally undertaken, provide a reasonably good indication of what actually occurs in practice. It must be acknowledged that incidence studies reveal what doctors *thought* they did rather than what they *actually* did and whether this in fact was the cause of the patient's death. In contrast to the Netherlands where there is a high level of knowledge and expertise about the efficient termination of life, in countries which prohibit euthanasia, doctors do not have this level of skill in this area. Any discrepancy between what doctors thought they did and what they actually did is, however, difficult to measure and in the interests of being able to use and compare the incidence data from a number of jurisdictions, it is necessary to proceed on the inevitably artificial assumption that the physicians in different countries have equal medical skills in the termination of life.

There is a considerable degree of consistency in the outcomes of surveys undertaken in a number of common law jurisdictions. In Australia, a questionnaire aimed at gauging the occurrence of euthanasia amongst doctors who had

been asked to perform it, was administered in a number of States: In Victoria, (an anonymous postal survey of 2000 doctors) 29% of doctors who had been asked by a patient to assist them to die had provided such assistance;⁵ in New South Wales, (also involving a sample of 2000 doctors) the same survey instrument recorded a positive response rate of 28% to this question.⁶ The questionnaire used in these studies was adopted by researchers in the United States and administered to 5000 doctors in the State of California. Approximately 23% of these respondents indicated that they had deliberately taken the lives of terminal patients who had asked them to so.⁷ Similarly, in the United Kingdom, a survey of National Health Service doctors in the United Kingdom (anonymous postal questionnaire sampling over 400 doctors) reported that approximately one third of the respondent doctors who had been asked for assistance in dying had taken active steps to end the life of a patient.⁸

These survey results unequivocally indicate that criminalising euthanasia does not prevent it from occurring, but simply serves to conceal such practices from public view and scrutiny. The fact that laws on the books are, at times, breached is not of itself surprising: indeed this occurs across the broad spectrum of crimes. What is significant is that we are talking about conduct by a well respected professional group involving potentially the most serious criminal liability, and yet when surveyed anonymously, a not insignificant proportion of doctors will admit to having practised euthanasia.⁹

Moreover, a culture of hidden and covert practices carries its own dangers. Aside from engendering distrust of the law, in the clinical context of euthanasia, it is likely to deter patients from raising the issue and to discourage doctors from consulting with colleagues because of fear of consequences.¹⁰ Consequently, they will not be able to benefit from criticism or support from their professional peers with regard to their involvement in these practices. It is also likely to encourage doctors to 'take things into their hands', even to the point where they unilaterally do what they think is best for the patient. Ultimately,

5 Kuhse H. and Singer P., 'Doctors' Practices and Attitudes Regarding Voluntary Euthanasia' (1988) 148, *Medical Journal of Australia*, 623.

6 Baume, P. and O'Malley, E., 'Euthanasia: Attitudes and Practices of Medical Practitioners' (1994) 161, *Medical Journal of Australia*, 137.

7 Note, 'Most California Doctors Favour New Euthanasia Law' (1988) 31, *Hemlock Quarterly*, 1-2.

8 Ward, B and Tate, P., 'Attitudes Among NHS Doctors to Requests of Euthanasia' (1994) 308, *British Medical Journal*, 1332: 38 of the 119 (32%) respondents answering this question (all of whom had indicated that they had been asked for such help). For further documentation of the evidence regarding the practices of doctors with respect to euthanasia, see M. Otlowski, 'Voluntary Euthanasia and the Common Law', above, 134-138.

9 To give some perspective to the figures cited above which indicate the incidence of euthanasia performed by doctors who have been asked to provide such assistance, surveys suggest that many doctors (according to some surveys, nearly 50%) have been asked to provide such assistance: see further M. Otlowski, 'Voluntary Euthanasia and the Common Law', above, 130-134.

10 See the findings of the study by Back, A., *et al.*, 'Physician Assisted Suicide and Euthanasia in Washington State: Patient Requests and Physician Responses' (1996) 275, *American Medical Association Journal*, 919, 923, 924.

this may entail performing euthanasia on patients who have not requested it: possibly in circumstances where the patient lacks competence and is unable to make such a request, or even where the patient is competent but is simply not consulted. Drawing on available empirical evidence which is outlined below, this paper seeks to show that not only is legal prohibition of euthanasia ineffective to prevent euthanasia from occurring, it creates an environment where both patients and doctors are put at risk.

There have been many surveys of doctors' attitudes as well as practices in relation to euthanasia in common law and other jurisdictions, a few of which have already been referred to above.¹¹ Of particular relevance for the purposes of this paper are the data which have been generated in Australia in a major national study. The empirical research that has been undertaken in that country is significant because it allows at least rough comparison with data from the Netherlands where a more permissive policy has been taken in relation to euthanasia. This is no mere coincidence: the design and methodology of this Australian study undertaken by Kuhse *et al*¹² was deliberately modelled on aspects of an earlier Dutch study¹³ to enable comparison of the position in practice of these two jurisdictions to be made.¹⁴

The Australian study, undertaken by way of postal survey between May and July 1996, involved a sample of 3000 doctors from all Australian States and Territories and sought to estimate, for the first time, the proportion of deaths in Australia involving end-of-life decisions. Participants were drawn from a random sample of active medical practitioners throughout Australia, selected from medical disciplines in which there are opportunities to be involved in medical end-of-life decisions. There was a response rate of 64%. One of the key findings of this study was that the incidence of termination of life without request in Australia was significantly higher than for euthanasia. Euthanasia, expressed as a percentage of all deaths in Australia, was found to occur at a rate of 1.7%.¹⁵ Ending of a patient's life without a concurrent explicit request occurred much more frequently, at a rate of 3.5% of all deaths,

11 See Otlowksi, M., 'Voluntary Euthanasia and the Common Law', above, 134-138; 292-332 for analysis.

12 Kuhse, H., *et al.*, 'End of Life Decisions in Australian Medical Practice' (1997) 166, *Medical Journal of Australia*, 191.

13 Maas, P. van der, Delden J. van, and Pijnenborg L., 'Euthanasia and Other Medical Decisions Concerning the End of Life' (1991) 338, *The Lancet*, 669; Maas, P. van der, *et al.*, 'Euthanasia, Physician-Assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands 1990-1995' (1996) 335, *New England Journal of Medicine*, 1699. The Dutch research is discussed further below.

14 As explained in the lead article reporting on this research, some aspects of the Dutch study could not be precisely replicated in Australia because of the different circumstances in this jurisdiction. One significant difference is that the Australian study did not involve a death certificate study as did the Dutch study but was confined to a survey of doctors and their recollections about past cases. Although questions asked were directly comparable, because of this difference in methodology, the results based on them are less directly comparable.

15 An additional 0.1% was recorded for physician-assisted suicide.

more than twice the rate of euthanasia.¹⁶ In some of these cases, (38%) there was some discussion with the patient, although not an explicit request for death to be hastened. In most of the remaining cases, the doctor did not consider the patient competent (i.e. capable of assessing his or her situation and making a decision about it.)¹⁷ However, there were instances, comprising 6% of these cases, where the patient was competent yet the decision was made without any consultation with the patient.¹⁸ Extrapolating from other survey evidence and similarities in results that have been found between Australia and other common law jurisdictions, there is no reason to believe that the results would be substantially different if a similar study were undertaken in the United Kingdom, or the United States.¹⁹

This greater incidence of termination of life without request in comparison with euthanasia must, at least in part, be attributable to the illegality of the practice and the lack of openness on the issue with the consequence that doctors are often taking this decision upon themselves. The study authors, while expressing no concluded view on this, also support the conclusion that because of the existing prohibition on the intentional termination of life, doctors are reluctant to discuss medical end-of life decisions with their patients. Also significant is the low rate of consultation by doctors with their colleagues: this was at a rate of 27% for both euthanasia and termination of life without request, confirming concerns that many doctors are likely to feel inhibited in broaching these matters with their colleagues.

Also of relevance in this context are research data from Belgium recently published in *The Lancet*.²⁰ Although distinct from the common law jurisdictions considered earlier, Belgium has also maintained a policy of prohibition of euthanasia under its criminal law,²¹ as indeed have most other European jurisdictions. The empirical research undertaken in this country by a team of researchers from a number of Belgium universities was also modelled on earlier Dutch research with the aim of estimating the frequency of certain end-of-life decisions. The results of this Belgium study are therefore readily comparable with the empirical data from Australia.

16 See also the recently published research of Douglas, C., *et al.*, 'The Intention to Hasten Death: A Survey of Attitudes and Practices of Surgeons in Australia' (2001) 175 *Medical Journal of Australia* 51 reporting on a survey involving 683 respondents which found a significantly higher incidence of non-requested than requested life termination by surgeons: 29 respondents (4.2%) had administered a bolus lethal injection in response to a sincere and unambiguous requested compared with 139 respondents (20.4%) who had given drugs with the intention of hastening death but without the explicit request of the patient.

17 Kuhse, H., *et al.*, 'End of Life Decisions in Australian Medical Practice', above, 193.

18 *Ibid.*, 194 Table 3.

19 See, for example, above, surveys documenting the involvement of doctors in euthanasia.

20 Deliens, L., *et al.*, 'End-of-Life Decisions in Medical Practice in Flanders, Belgium: A Nationwide Survey' (2000) 356, *The Lancet*, 1806.

21 The prohibition on euthanasia is contained in the Belgium *Criminal Code*. However, legislation is currently before the Belgium Parliament for the legalisation of euthanasia. For further discussion, see the contribution by Adams, M., 'Euthanasia, 'The Process of Legal Change in Belgium' in this Issue.

The research was done in Flanders, the Dutch speaking region of Belgium, where a majority (60%) of the population lives.²² Using the same research design in the earlier Dutch research, a random sample of death certificates was identified (3999 in total) and questionnaires sent to the 2,585 physicians who had signed them. The overall response rate was 52%. The results of the study are based on 1925 questionnaires (48% of the questionnaires sent out).²³ Interesting comparisons can be drawn between the Belgium and Australian data.²⁴ The frequency of euthanasia in Flanders was similar to that in Australia (1.1% of all deaths in Flanders compared with 1.7% of all deaths in Australia).²⁵ Furthermore, the rate of euthanasia performed without an explicit and concurrent request from the patient was also close to the Australian result (3.2% of all deaths in Flanders compared with 3.5% of all deaths in Australia). In the majority of the Flanders' cases there was no discussion or previous wish stated (62%). In a not insignificant proportion of cases (12%) the patient was competent at the time of the decision.²⁶ The rate of consultation with colleagues was somewhat higher than that recorded in the Australian study: 48% in respect of euthanasia and 40% in cases of termination of life without request.

These research data from Belgium suggest that these practices are not peculiar to common law jurisdictions or to the particular approach of the common law, but rather, are the product of an outright prohibition on euthanasia under the criminal law, however this might be achieved. The reality is that strict laws prohibiting euthanasia in Australia and in Flanders, Belgium, have not prevented doctors in these jurisdictions from practising euthanasia. Moreover, in a worrying trend, these jurisdictions have recorded a significantly higher incidence of termination of life without request than for euthanasia: in Australia 3.5% of all deaths as compared with 1.7% for euthanasia; in Flanders 3.2% of all deaths as compared with 1.1% for euthanasia. These results directly challenge the effectiveness of a policy of criminal prohibition in controlling euthanasia. This theme is explored later in this paper, following consideration of the law and practice in the Netherlands.

22 See the contribution by Mortier, F. and Deliëns, L., 'The Prospects of Effective Legal Control on Euthanasia in Belgium' in this Issue.

23 In total, 1930 questionnaires were returned but 5 questionnaires had to be excluded because of incomplete or inconsistent answers: Deliëns, L., *et al.*, 'End-of-Life Decisions in Medical Practice in Flanders, Belgium: A Nationwide Survey,' above, 1807.

24 Consideration is given below to a comparison of the results of both the Belgium study and the Australian research with empirical data from the Netherlands.

25 As in Australia, there was an additional 0.1% of cases in Flanders recorded for physician-assisted suicide.

26 Deliëns, L., *et al.*, 'End-of-Life Decisions in Medical Practice in Flanders, Belgium: A Nationwide Survey', above, 1809, Table 4.

2.3 Other failings of the common law's approach to euthanasia

The failure of the criminal prohibition to prevent the practice of euthanasia is only one aspect of more general shortcomings of the law in this area. There are, in fact, a number of other aspects of the law in practice which are unsatisfactory, including further discrepancies between the law in theory and the law in practice. As noted earlier, under strict legal principles, the common law treats euthanasia as murder with no apparent room for compromise. In practice, however, a range of strategies are invoked along the continuum of the criminal justice system to avoid the conclusion that a doctor is guilty of murder, ranging from want of prosecution,²⁷ spurious jury acquittals against the weight of the evidence,²⁸ and lenient sentences.²⁹ In short, the picture is largely one of non-enforcement of the law.

Although the motives of those engaged in these strategies are perfectly understandable, this duplicitous approach is objectionable in several respects. It is open to criticism for its dishonesty, relying on various legal devices or tactics to get doctors 'off' and because it results in the inconsistent and unpredictable operation of the criminal law. This is well illustrated by contrasting cases where doctors who have been prosecuted for euthanasia have been acquitted and 'walked free' with cases where they have experienced the fuller brunt of the law such as the case involving Dr Cox.³⁰ Cox, a consultant rheumatologist, was convicted of the attempted murder of a terminally ill patient who had died following the administration of a large dose of potassium chloride.³¹ Following an uncompromising direction to the jury from Justice Ognall, Dr Cox was found guilty by a majority verdict. A term of imprisonment of 12 months was imposed but the sentence was suspended in recognition of the fact that the public interest would not be served by immediately jailing the defendant. Whilst this may seem a lenient sentence, it must be remembered that the charge was for attempted murder rather than murder, and the judge had the discretion to impose a lighter penalty, including the possibility of a conditional discharge. The *Cox* case is significant because it demonstrates that doctors acting *bona fides* can be found criminally liable for taking active steps to hasten the death

27 There have been a number of instances of non-prosecution in respect of Canadian doctors who have apparently been involved in assisting their patients to die: e.g. Dr Peter Graff in North Vancouver; a Quebec doctor and a doctor from Manitoba: see further, Otowski, M., 'Voluntary Euthanasia and the Common Law', above, 146. Note, also in this context the case of Dr Timothy Quill: although he had publicly admitted assisting a cancer patient to commit suicide, a grand jury refused to indict him on charges of assisting suicide.

28 E.g. *People v Sander* (unreported) *NY Times*, 10 March 1950; *People v Montemarano* (unreported) (1974) Nassau County Court (NY); *People v Rosier* (unreported) *Washington Post*, 2 Dec. 1988; *R v Carr* (unreported) *Yorkshire Post*, 12 Nov. 1986; *R v Moore* (1999) discussed by Arlidge, A., 'The Trial of Dr David Moor' (2000) *Criminal Law Review*, 31.

29 E.g. *People v Hassman* (unreported) *NY Times*, 20 Dec. 1986. For detailed analysis, see Otowski, M., 'Voluntary Euthanasia and the Common Law', above, 140-148.

30 *R v Cox* (1992) 12, *BMLR*, 38 (Winchester CC).

31 The charge was for attempted murder rather than murder because the deceased's body had been cremated and therefore the cause of death could not be conclusively established.

of a suffering patient and thus highlights the legal vulnerability of doctors who engage in these practices.

Inconsistencies in the application of the law create potential for arbitrary and capricious results and sends confusingly mixed signals to the medical profession. Moreover, because of the discrepancies between legal principles and the law in practice, there is no established legal precedent with reference to which medical decisions in respect of terminal patients can be made and evaluated.³² Furthermore, the secrecy inevitably surrounding the practice in a climate of illegality results in lack of medical guidance, thus jeopardising the quality of medical decision-making in this area.

There are other aspects of the common law geared to 'liability avoidance': in particular, the common law's permissive approach to the administration of palliative drugs to the terminally ill which may hasten death and the legal characterisation of withdrawal of life support as an omission rather than an act. These 'liability avoidance' strategies, which have been more fully canvassed elsewhere, whilst readily understandable, create a situation where the legal position is not what it seems.³³ When viewed in conjunction with other aspects of the law's haphazard application in this area, the conclusion seems inescapable that leaving the fate of doctors to this kind of legal manoeuvring encourages cynicism and disrespect for the law. There is a need for greater honesty and clarity to overcome these discrepancies and achieve a better fit between law and practice. If society has reached the point where such medical conduct is regarded as acceptable and not deserving of punishment, this should be more directly reflected in our laws. Arguments for review of the common law's policy of prohibition can also be mounted on the basis of protecting the rights and interests of patients: so long as the practice of euthanasia occurs but remains hidden and uncontrolled, the rights and interests of patients are not being adequately protected. There is already ample evidence of this in the data regarding doctors' practices, with euthanasia not infrequently being performed without a concurrent and explicit request.

3. The Netherlands' Experience: Regulation Rather than Prohibition

3.1 Key features of the Dutch approach to euthanasia

The Netherlands' experience with euthanasia has been a truly remarkable one which has inevitably attracted interest around the world. Other papers in this special Issue deal with the historical development of the law and policy in relation to euthanasia³⁴ and its operation in practice³⁵ and there is little to be

32 See also Wilson, J., *Death by Decision*, Philadelphia, Westminster Press (1975) 165.

33 Otłowski, M., 'Voluntary Euthanasia and the Common Law', above, 152-184.

34 See, in particular Weyers, H., 'Euthanasia: The Process of Legal Change in the Netherlands.' in this Issue.

gained by traversing the same ground in this paper. Rather, this section seeks to distil the key features of the Dutch approach which distinguishes it from that adopted in other countries and to evaluate its operation.

Commencing with the initiative of the courts, the Netherlands has for many years adopted a significantly more permissive approach to euthanasia than that taken by other jurisdictions. Essentially, it has been based on a policy of regulation rather than outright prohibition, although, up until recently, euthanasia has remained a criminal offence under Dutch law.³⁶ The Netherlands' permissive policy on euthanasia was not the creature of governmental fiat but has evolved over time. A synthesis of factors, including case law developments, medical guidelines, prosecutorial policy, institutional protocols, and ministerial decree gave rise to a situation of legal tolerance or '*de facto*' legal acceptance of euthanasia, performed in accordance with established guidelines. What this has meant in practice, is that Dutch doctors have been able to perform euthanasia, with full assurance that they will not be held criminally accountable, provided that they adhere to the guidelines for careful practice.

3.2 Moves towards legalisation of euthanasia

Although widely regarded in the Netherlands as an appropriate policy direction, there had been differences of view as to whether more formal steps towards actual legalisation of euthanasia were required. Whilst some supported the retention of the prohibition under criminal law as symbolically significant, for others there was concern about the ambivalent legal status of euthanasia which was seen as an impediment to achieving complete openness and effective control of the practice. Numerous reform proposals had been advanced and debated over the years. Only recently, however, has legislation been passed, amending the *Criminal Code* to give statutory protection to doctors who adhere to the requirements of careful practice (now specified in this legislation)³⁷ in performing euthanasia on request or assisting in a suicide and re-

35 Klijn, A., 'Will Doctors' Behavior Be More Accountable Under the New Dutch Regime?' in this Issue.

36 Article 293 *Criminal Code* 1886. Note also Article 294 which contains a prohibition on assisted suicide.

37 See the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act*, Chapter II which specifies that in order to comply with the due care criteria referred to in Article 293 of the *Criminal Code* as amended, the attending physician must:

- a. be satisfied that the patient has made a voluntary and carefully considered request;
- b. be satisfied that the patient's suffering was unbearable and that there was no prospect of improvement;
- c. have informed the patient about his situation and his prospects;
- d. have come to the conclusion, together with the patient, that there is no reasonable alternative in the light of the patient's situation;
- e. have consulted at least one other, independent physician, who must have seen the patient and given a written report in the due care criteria referred to in a-d above; and

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port the act to the Coroner (as now formally required under the *Burial and Cremation Act*.) The actual changes to euthanasia law (aside from formalising the *de facto* legal recognition already given to the practice) are relatively few.³⁸ The fundamental structures that had evolved over the years to support and regulate the practice of euthanasia in the Netherlands, including the Regional Assessment Committees set up in 1997, remain in place, although the new laws do make some changes to their operation.³⁹

3.3 Empirical evaluation of the practice of euthanasia in the Netherlands

As one might expect, the Netherlands' experience with euthanasia has been the subject of intense scrutiny because of the unique opportunity it offers to assess the effects of State-sanctioned euthanasia upon the law, medicine, health care and social policy. For some, a permissive policy on euthanasia has been seen as tantamount to stepping on to the 'slippery slope,' with allegations being made of an extensive and uncontrollable practice although such assertions have generally been based on an oversimplistic analysis.⁴⁰ Nowhere has the interest in ascertaining the true situation been greater than in the Netherlands itself. Through the work of government commissioned inquiries as well as publicly funded research, intensive efforts have been made to gather empirical data to determine the true operation of the practice of euthanasia, going far beyond any surveys undertaken in other jurisdiction. This process of self-analysis and critical introspection has produced a wealth of data on the Netherlands' situation and has laid to rest some of the more exaggerated claims about the extent and nature of the practice.

In 1990, the then coalition Government established a committee under the Chairmanship of Professor Rummelink, Procurator-General of the Dutch Supreme Court, to conduct a nation-wide study into the practice of euthanasia in the Netherlands. The Rummelink inquiry was a complex, multi-pronged study, involving interviews with doctors, questionnaires distributed to doctors of a sample of deceased persons (the death certificate study), as well as a prospec-

f. have terminated the patient's life or provided assistance with suicide with due medical care and attention.

38 Included amongst these are the fact that under the new laws, the requirement of consultation and reporting have been made conditions for legality. Further, advance directives are expressly acknowledged as a valid means of communicating a request for euthanasia. The legislation also provides for euthanasia at the request of minors in some circumstances.

39 Once the legislation comes into effect, the decisions of the committees, formerly only of advisory status to the prosecuting authorities, will be final. Cases will only be referred to the prosecuting authorities in circumstances where the due care criteria have not been complied with.

40 See, for example, Fenigsen, R., 'A Case Against Dutch Euthanasia' (1989) 19, *Hastings Center Report*, 22, where he notes that figures as high as 18,000 or 20,000 deaths per year have been mentioned. Note also Keown, J., 'Euthanasia in the Netherlands: Sliding Down the Slippery Slope?' in *Euthanasia Examined: Ethical, Clinical and Legal Perspectives*, Keown, J. (ed.), Cambridge, Cambridge University Press (1995) 261.

tive component.⁴¹ Although some aspects of the results have been subject to differing interpretations,⁴² there has been widespread acceptance that the research findings accurately reflect medical practice in the Netherlands. This is attributable to a number of factors, including the integrated study design permitting cross validation of results, the anonymity and immunity offered to participants, and the resulting high participation rate from the medical profession. There was a major follow up to the Rummelink study in 1995 allowing an evaluation of the practice of euthanasia in the Netherlands over the period 1990-1995.⁴³ The results from these two studies provide no support for claims of a slippery slope with regard to the practice of euthanasia in the Netherlands. Indeed, when viewed in light of empirical data from other jurisdictions which maintain a policy of prohibition, it appears that there is little difference in the incidence of euthanasia in the Netherlands and jurisdictions such as Australia where the practice is illegal. There are, however, significant differences in the rate of termination of life without request as between these jurisdictions. These data debunk the theory of a slippery slope brought about through more tolerant laws and in fact suggest that the dangers are precisely in the other direction: i.e. there are greater dangers inherent in an ineffective policy of legal prohibition.

According to the 1990 study, euthanasia was occurring at a rate of 1.8% of all deaths in the Netherlands (a total of 2,300 cases in 1990).⁴⁴ In the same study, the incidence of cases of termination of life other than at the explicit and persistent request of the patient was found to be 0.8% of all deaths (approximately 1,000 cases). In more than half of these cases, euthanasia had already been discussed with the patient or the patient had, at an earlier time, expressed a wish for euthanasia if his or her suffering became unbearable. For the remainder, aside from a few isolated cases which had occurred a considerable time ago, the cases involved seriously ill and dying patients who clearly suffered severely and were no longer able to take a decision.⁴⁵

The 1995 study recorded no increase in the incidence of cases of termination of life other than at the explicit and persistent request of the patient in the intervening period (in 1995 the figure was to 0.7% of all deaths – a statistically insignificant decline from 0.8% recorded in 1990.) This outcome had been anticipated by commentators in the Netherlands in the wake of the earlier study: the view being that growing openness with regard to end-of life issues would

41 Maas, P. van der, *et al.*, *Euthanasia and Other Medical Decisions Concerning the End of Life: An Investigation Performed Upon Request of the Commission of Inquiry into the Medical Practice Concerning Euthanasia*, Health Policy Monographs, Vol. 2, Amsterdam, 1992.

42 This was particularly the case in relation to the category of cases involving termination of life other than at the patient's explicit and persistent request (representing a total of approximately 1,000 deaths).

43 Maas, P. van der, *et al.*, 'Euthanasia, Physician Assisted Suicide and Other Medical Practices Involving the End of Life in the Netherlands, 1990-1995', above.

44 Physician-assisted suicide accounted for 0.2% of all deaths in the Netherlands.

45 Maas, P. van der, *et al.*, *Euthanasia and Other Medical Decisions Concerning the End of Life*, above, 69.

result in a decrease in this category.⁴⁶ There was, however, some evidence of increase in the incidence of euthanasia (from 1.8% of all deaths in 1990 to 2.4% in 1995). A number of factors are thought to have contributed to this increase, including increased mortality rates as a consequence of the ageing of the population, and increase in the proportion of deaths from cancer and the increasing availability of life-prolonging techniques.⁴⁷ Significantly, the 1995 study found no evidence of a diminution of standards in the practice of euthanasia or of decline in the severity of illnesses for which euthanasia was performed.⁴⁸ In a majority of cases, there was prior consultation with colleagues: a rate of 83% in respect of cases of euthanasia and 59% in cases where life was ended without an explicit request. In short, euthanasia was assessed to be an exceptional but accepted part of medical practice in the Netherlands: a practice which is performed rarely, with reluctance and as a last resort.⁴⁹

As leading Dutch commentators have concluded, these findings provide no empirical basis for the assertion that the Dutch have already slid a bit down the slippery slope because there is no evidence that they have moved at all (let alone, that the policy of quasi-legalization of euthanasia was responsible for the slide).⁵⁰ What is particularly interesting is the comparison of the data from the Netherlands with empirical data on the extent and circumstances of the practice of euthanasia from other jurisdictions where a policy of prohibition of euthanasia has officially been in place. This is the subject of consideration in the following section of this paper and provides some telling insights into the effectiveness of the differing approaches to the legal control of euthanasia.

4. An Evaluation: What Lessons can be Drawn from Comparative Law?

4.1 Probing the meaning of 'effective legal control'

At the core of this comparative analysis lies the question: Which approach offers more effective legal control of euthanasia? – a policy of prohibition, as exists under common law, or a policy of legalisation, as has existed in the Netherlands – for many years on a *de facto* basis; more recently by force of legislation. However, before this analysis can be meaningfully undertaken, some attention needs to be given to the notion of 'effective legal control of euthanasia'

46 Pijnenborg, L., *et al.*, 'Life Terminating Acts Without Explicit Request of Patient' (1993) 341, *The Lancet*, 1198-1199.

47 Maas, P. van der, *et al.*, 'Euthanasia, Physician Assisted Suicide and Other Medical Practices Involving the End of Life in the Netherlands, 1990-1995', above, 1703.

48 *Ibid.*, 1705.

49 Griffiths, J., Bood, A. and Weyers, H., *Euthanasia and Law in the Netherlands*, Amsterdam, Amsterdam University Press (1998) 260.

50 *Ibid.*, 301-302. This conclusion is also in accord with the view of the authors of the 1995 study: Maas, P. van der, *et al.*, 'Euthanasia, Physician Assisted Suicide and Other Medical Practices Involving the End of Life in the Netherlands, 1990-1995,' above, 1705.

so that some qualitative evaluation can be made in addition to the comparison of empirical data.

The word 'control' used as a noun, refers to the power of directing, or giving command. Conversely, 'out of control' is defined as no longer subject to guidance. Used as a verb, 'control' means to hold in check or regulate.⁵¹ The phrase 'legal control' conveys the meaning that control is achieved through the law, but says nothing as to how the law achieves this: whether by strict legal prohibition or otherwise, for example, through legalisation or decriminalisation. There is, however, a tendency to assume that a strict policy of prohibition would achieve greater control than a more permissive approach and that it would be more protective of the rights of patients. Importantly, in attempting to evaluate the level of protection afforded under the different models, attention must be focused on actual control rather than merely identifying enforcement mechanisms which may exist but which may be ineffective in securing the control they are intended to achieve.

Some observations can also be made as to the expectations that the phrase 'effective legal control of euthanasia' might reasonably give rise to. This implies a degree of visibility and openness in the practice as there is no prospect of controlling practices which are performed secretly. Further, it suggests accountability for those performing euthanasia in the sense that their conduct must be open to scrutiny. It also carries the connotation that the practices performed are performed safely in accordance with accepted methods and, where applicable, guidelines. Above all, high priority must be given to the need for a voluntary process, because protection of patient autonomy represents the surest safeguards against abusive practices. Finally, (although this is not proposed as an exhaustive list),⁵² in order for there to be effective control, there needs to be a considerable degree of certainty and predictability in the law.

4.2 Assessment of the 'effectiveness' of a policy of prohibition to 'control' euthanasia

When evaluated in the light of the distinctive features of 'effective legal control' of euthanasia which have been identified, it is readily apparent that none of these features are present in common law or other jurisdictions where a strict criminal law prohibition applies to euthanasia. From the earlier analysis, it is evident that the common law's policy of criminal prohibition is ineffective to control euthanasia. Doctors, although generally a law abiding professional group, apparently do not see themselves as bound by the criminal law prohibition on deliberate taking of life and the classification of this as murder. One

51 *The Concise Oxford Dictionary of Current English*, 7th ed, Oxford, Oxford University Press (1982), 206.

52 See further the very useful analysis in Griffiths, J., Bood, A. and Weyers, H., *Euthanasia and Law in the Netherlands*, above, 260 ff.

can only speculate why this is so: it seems, at least in part, because the criminal law is seen as too removed from the realities of the doctor/patient relationship and is therefore not regarded as relevant or applicable. Interpretation of why doctors act in certain ways is inevitably a very complex matter and legal rules represent only one of a number of external influences, including professional norms and medical ethics. Thus, we have a situation of *purported* or *ostensible* legal control: The existence of the legal prohibition gives the appearance of effective control, but empirical evidence demonstrates that this is illusory as control in practice is non-existent. Even more concerning, this approach to euthanasia appears to create an environment where unauthorised practices, performed other than at the explicit request of the patient, flourish.

4.3 Evaluating the effectiveness of 'legal control' under the Netherlands' model

This situation is usefully contrasted with the position in the Netherlands where there is much more effective control of euthanasia, although by no means complete.⁵³ Measured against the indicia of visibility, accountability, safety, and compliance with guidelines focussed on the protection of the patient, the Netherlands fares infinitely better in its attempts to control euthanasia. Euthanasia is practiced openly in the Netherlands with consultation among colleagues being the norm. Many doctors report cases of euthanasia to the authorities in which they have been involved.⁵⁴ Reported cases are investigated and open to scrutiny, thus ensuring that doctors are held accountable for their conduct.⁵⁵ The fact that there have been very few prosecutions of doctors in the Netherlands arising from these investigations supports the conclusion that there is general compliance with the established guidelines for careful practice of euthanasia. This, in turn, helps to instil confidence in the Dutch medical profession's conduct in relation to euthanasia. Furthermore, although, until recently, euthanasia has had precarious legal status in the Netherlands, there has been a high degree of certainty and predictability in the law's application. Significantly, the Dutch

53 For discussion of the limitations on control in the Dutch context, see Griffiths, J., Bood, A. and Weyers, H., '*Euthanasia and Law in the Netherlands*', above, Chapters 6 and 7.

54 Following the introduction of a new notification procedure for reporting of cases, reporting rates had risen from approximately 18% in 1990 to about 41% in 1995: Wal, G. van der, *et al.*, 'Evaluation of the Notification Procedure for Physician-Assisted Death in the Netherlands' (1996) 335, *New England Journal of Medicine*, 1706, 1710. However, over the past few years, there seems to have been a decline in reporting rates. For analysis, see Klijn, A., 'Will Doctors' Behavior Be More Accountable Under the New Dutch Regime?' in this Issue.

55 Since 1997, responsibility for investigation of cases of euthanasia has resided with the multidisciplinary regional assessment committees, each composed of a doctor, a jurist and an ethicist. These committees, in turn, report to the Committee of Procurators-General which, subject to the approval of the Minister for Justice, has responsibility for deciding whether or not to initiate criminal proceedings. As noted earlier, once the law comes into effect, these committees will have final decision-making responsibility, and will only refer cases to the prosecuting authorities in circumstances where the carefulness requirements have not been complied with.

doctors and the Dutch Medical Association (KNMG) have taken an active role in contributing to legal policy on euthanasia. Developments in that jurisdiction have highlighted the importance of open dialogue and co-operation between the State regulators and the medical profession in developing an effective policy on euthanasia.

In other jurisdictions, however, where the law's policy is to prohibit euthanasia, no such guidelines are in place and whether or not a doctor accedes to a patient's request will more likely depend on the doctor's own attitude to euthanasia and his or her willingness to take risks rather than on the compelling nature of the patient's request or other objective criteria. Decisions are accordingly left to the judgment of individual doctors and in the light of the evidence, canvassed earlier, it seems that in practice, doctors are often taking matters in their own hands, with euthanasia being performed, more often than not, other than at the explicit request of the patient. So far from instilling confidence in the medical profession, the data from jurisdictions which maintain a policy of prohibition, gives rise to genuine concerns about the appropriateness of doctors' practices. Thus, in addition to the greater accountability of doctors in the Netherlands, and the greater visibility of their practices, there would appear to be some qualitative differences in the practice of euthanasia as between, on the one hand, the Netherlands and on the other, common law jurisdictions such as Australia or non-common law jurisdictions such as Belgium. To a large extent, this can be attributed to the Dutch guidelines on euthanasia developed by the courts, with the assistance of the Dutch medical profession, and now set down in legislation. The requirements of careful practice comprising these guidelines consist of both substantive and procedural norms aimed at ensuring that euthanasia is performed in optimal circumstances.

4.4 Comparative data from countries with different approaches to the legal control of euthanasia

Further insights into the relative success of each approach can be gleaned from a comparison of the empirical data from Australia and Flanders in Belgium (both jurisdictions where euthanasia has been prohibited under criminal law), with the data from the Netherlands. The first observation is that there does not appear to be a great deal of difference in the rate of euthanasia as between these jurisdictions, notwithstanding the starkly different policy approach in the Netherlands compared with the other two jurisdictions. This is significant, not only to demonstrate the ineffectiveness of a policy of prohibition in preventing the occurrence of euthanasia, but also to show that a more tolerant law will not necessarily result in a significantly higher incidence of the practice.

Although there are variations in the data from Australia and Belgium, there are some striking similarities in the data from those jurisdictions when con-

trasted with data from the Netherlands.⁵⁶ Of particular significance in this regard is the fact that there is a substantially lower incidence in the Netherlands of cases of euthanasia other than at the explicit concurrent request of the patient than is the case in either Australia or Flanders, Belgium, where a policy of prohibition prevails: 0.7% of all deaths in the Netherlands, compared with 3.5% of all deaths in Australia, and 3.2% of all deaths in Flanders, Belgium, which is four or five times the rate in the Netherlands. Further, in these jurisdictions, there was a higher proportion of cases where although the patient was competent, there was no consultation with the patient.⁵⁷ Also of interest is a comparison of the rate of consultation across these jurisdictions: The Netherlands recorded the highest rates of consultation with colleagues.⁵⁸

Viewed objectively, the evidence points to the conclusion that a restrictive policy on euthanasia is, in fact, less protective of the rights of patients.⁵⁹ The substantially higher incidence of termination of life without request in Australia and Belgium than in the Netherlands and the lower incidence of consultation with colleagues prior to performing euthanasia indicate that there are greater risks inherent in laws which prohibit euthanasia, but which are in practice flouted, than exist when genuine attempts are made to control and regulate the practice as has occurred in the Netherlands.

This comparative evaluation demonstrates the fallacy of the proposition that prohibition of euthanasia equates to control: practically speaking, there is no scope for control in circumstances where the practice remains hidden. Equally, it undermines assertions that the absence of a strictly enforced criminal prohibition results in an uncontrolled practice of euthanasia. The Dutch experience has shown that more effective legal control can be achieved through easing the criminal law prohibition (or at least its enforcement in practice).⁶⁰ Not only do the comparative data tend to refute claims of a 'slippery slope', it supports the argument that legislation, combined with a system of

56 For example, the rate of euthanasia and termination of life without request appears to be higher in Australia than in Flanders, Belgium: for euthanasia, 1.8% of all deaths compared with 1.2% and in the case of termination of life without request, 3.5% of all deaths compared with 3.2%.

57 Australia, 6% (see Kuhse, H., *et al.*, 'End of Life Decisions in Australian Medical Practice', above, 193, Table 3); Flanders, Belgium, 12% (figure supplied by Professor Freddy Mortier, member of the Belgium legal research team); Netherlands, 0% Maas, P. van der, *et al.*, *Euthanasia and Other Medical Decisions Concerning the End of Life*, above, 67, 69 (in the relevant study period there were no such cases although in interviews, two cases dating back to the early 1980s were uncovered in which a life terminating act had been performed on a competent patient without any prior discussion); note also Maas, P. van der, *et al.*, 'Euthanasia, Physician-Assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands 1990-1995,' above, 1701, where there is, at least indirect, confirmation of the fact that in no cases was life terminated in respect of a competent patient without some form of prior consultation with the patient.

58 Based on the 1995 data, there was consultation with colleagues in 83% of cases involving euthanasia and 59% of cases of termination of life without request (Australia: 27% for each category; Flanders, Belgium 48% and 40% respectively).

59 This is also the conclusion of Deliens, L., *et al.*, 'End-of-Life Decisions in Medical Practice in Flanders, Belgium: A Nationwide Survey,' above, 1810.

60 Griffiths, J., Bood, A. and Weyers, H., *Euthanasia and Law in the Netherlands*, above, 302.

regulation, would be likely to reduce the risk of abuse and idiosyncratic decision-making and ultimately would offer greater protection to patients. It stands to reason that if a lawful means is established for doctors to assist their patients to die which, subject to certain conditions, provides an immunity from criminal liability, doctors would prefer to seek the protection of the law by complying with its terms, rather than take the risk of incurring serious criminal liability.

5. Conclusion

We have seen that common law jurisdictions prohibit euthanasia, indeed, this has been the standard response of the criminal law to euthanasia in most countries around the world. In many respects, this is an easy and convenient position to take in view of the longstanding status quo, the widespread belief that this is consistent with the preservation of life, and the fact that moves to change the law in this area are inevitably controversial. Whilst it may appease the consciences of some that a 'strong' or 'strict' position is being taken against euthanasia, often overlooked are the implications of such an approach, in particular, the inconsistencies and distortions that arise in the operation of the law in practice, and the lack of protection that such an approach in fact provides.

An attempt has been made in this paper to look objectively at the evidence which is available to evaluate the advantages and disadvantages of each approach. It is submitted that if this is done even-handedly and dispassionately, the manifest failure of the prevailing policy of prohibition in common law and other jurisdictions, in contrast to a more tolerant approach, becomes apparent. In discussions of euthanasia, it is often assumed that society has a choice of not permitting it (and therefore having no euthanasia) or beginning to permit it. However, the available evidence shows that this is flawed premise from which to begin. Rather, the choice we face is whether we seek to regulate and control the practice of euthanasia or whether it is left unregulated and unchecked, which creates greater risks for both doctors and patients.

In light of the conclusions that have already been drawn in this paper, it is submitted that in order for euthanasia to be effectively controlled, the prevailing policy of criminal prohibition needs to be replaced with a more open and intellectually honest approach which permits and, in accordance with medical norms, regulates euthanasia under specified conditions. Importantly, such an approach would reduce the risk of unacceptable practices and thereby afford greater protection for patients. It would also enhance the quality of medical decision-making in this area, encouraging professional discussion and guidance. Ultimately, it would instil greater certainty and predictability in the law.

The Netherlands' experience provides valuable guidance for the effective control of euthanasia and demonstrates that this can be done in a context which supports the integrity and professionalism of doctors and respects the rights and interests of patients. Yet, although the lessons from comparative law are

becoming clear in the light of growing empirical evidence from both the Netherlands and countries which have had a strict policy of prohibition such as Australia and Belgium, there appears to be a distinct reluctance in most jurisdictions to learn from this experience. The real question is whether the law and policy makers in these jurisdictions have the courage and the will to learn and benefit from these lessons.

Will Doctors' Behaviour Be More Accountable Under the New Dutch Regime? *Reporting and Consultation as Forms of Legal Control*

Albert Klijn

1. The Question: How Can Legal Rules be Made Effective?

One may characterise Dutch policy on euthanasia as predominantly 'pragmatic'. Not in the current pejorative sense of the word that suggests that moral considerations are subordinated to a purely practical weighing up of pros and cons, but in the original sense of the word: dealing with matters according to their practical significance. As we know from Weyers, the Dutch debate on the permissibility of euthanasia was, from the beginning, framed in terms of guidelines – later to become known as the 'requirements of careful practice' – which were intended to ensure that the decisions made by individual doctors be socially acceptable.¹ The medical profession and the judiciary were the principal actors in this debate. Although the medical profession, represented by the Royal Dutch Medical Association (KNMG), initially stressed that in formulating the guidelines it was taken no position on the permissibility of euthanasia, the guidelines in effect expressed some general norms that society should use in judging the behaviour of the doctors.² In this way, the professional organisation formulated 'bottom up' norms to which individual members should conform. The judiciary, by listening to the ideas voiced within the professional group, was able to formulate legal criteria that enjoyed general support among doctors. Since the mid-1980s, doctors who comply with the 'requirements of careful practice' are no longer criminally liable for euthanasia.

These requirements consist of both substantive and procedural norms. The first concern the patient's request and suffering, the latter involve a number of procedural steps doctors are supposed to follow.³ The procedural requirements are fundamental to the acceptability of euthanasia. Two of them are of particular importance. The *consultation requirement* provides that before a doctor performs euthanasia, he must consult at least one other doctor. The *reporting requirement* provides that the doctor who has performed euthanasia must report

1 See Weyers, H., 'Euthanasia: The Process of Legal Change in the Netherlands', in this Issue.

2 The Association proceeded in this cautious way in order to prevent a schism within the organisation similar to the one that had taken place in the early seventies as a result of the Association's position on abortion.

3 With respect to these 'requirements' it is important to make a clear distinction between those requirements which are enforced by criminal law and those which are enforced by medical disciplinary law.

this to the relevant authorities. The two requirements are linked to different stages in the process of euthanasia and so contribute differently to societal control: the consultation requirement embodies control *a priori*, the reporting requirement control *a posteriori*. The two requirements can be regarded as attempts to make doctors accountable for their behaviour.

However, it is one thing to formulate legal rules and quite another to ensure they are effective. It is the quest for the increased effectiveness of legal policy on euthanasia that inspires my reflection in this paper on the question: *What are the legal conditions under which doctors will decide to consult or to report?* Do different types of regulation make any difference in the consultation or reporting behaviour of doctors with regard to euthanasia?

Since the early 1990s the Dutch government has been experimenting with various ways of organising the control structure. In the Fall of 1998, new non-criminal regional assessment committees came into existence, in charge of assessing the behaviour of doctors who report euthanasia. The Law on the Termination of Life on Request, enacted in 2001, not only legalised euthanasia but simultaneously strengthened the position of these new bodies. However, the first results of the 1998 intervention seem to raise serious questions about the assumptions on which the new policy was based. The objective of this reflection is to bring some analytic order to the debate on whether or not the policy adopted will ultimately prove to contribute to the original goal of both the Government and the medical profession: a high degree of accountability regarding the behaviour of doctors that potentially shortens life.⁴

In the following, I first sketch the development of the two requirements: what precisely do they require doctors to do? Secondly, based on the findings of empirical research, I discuss the extent to which doctors comply with these rules. In order to do so, especially with regard to reporting, I will have to overcome some difficulties caused by the absence of the data needed to evaluate the effectiveness of Dutch policy over time. The approach I will propose not only provides us with the descriptive information we need, it also raises the question why doctors behave the way they do, especially in reaction to the recent changes in the way in which the control of euthanasia is organised. Thirdly, I will try to test an apparently plausible answer to that question by examining whether their reporting behaviour relates to the degree to which they can feel secure under a given control regime.

2. The Accountability Requirements: Law in the Books

2.1. The consultation requirement

The first time the issue of 'consultation' – as a procedural requirement in *statu nascendi* – seems to have been mentioned in connection with 'medical behav-

⁴ In this contribution I mostly deal with general practitioners because most euthanasia cases are carried out by them, and most of the available empirical research concerns their practice.

behaviour that potentially shortens life' was in the ruling of the Amsterdam Court of Appeal in 1969 in the case of *Mia Versluis*.⁵ The case was on appeal from the Medical Disciplinary Tribunal against the anaesthetist involved in the case, who had proposed to the patient's father to refrain from further treatment that was probably necessary to keep her alive. To the father the proposal amounted to what he called 'euthanasia' and for this reason he lodged a complaint with the medical disciplinary authorities. He lost the case, but appealed.⁶ The Medical Inspector considered that the behaviour of the anaesthetist was not incorrect, judged from a substantive point of view, but he argued that such an important and irreversible decision requires the utmost care, and that collegial consultation is an absolute and indispensable precondition that should have taken place before the proposal was made. However, the Court of Appeals did not convict the doctor for not having consulted, arguing that consultation was not yet common practice.⁷

Nearly ten years later, consultation had become a legally binding requirement, at least for euthanasia. Three developments were important in this regard. First, the 1981 ruling of the Rotterdam District Court on the *Wertheim* case.⁸ The court formulated a number of requirements, among them: 'the decision to give assistance and the assistance itself must exhibit the utmost care, which includes discussing the matter with another doctor if the patient's condition is in the terminal phase, and if the patient has not yet reached this phase, consulting other experts such as a psychiatrist, psychologist or social worker'.⁹ From that point on, the consultation requirement has been consistently upheld by Dutch courts.¹⁰ Secondly, the 1984 report of the Board of the Royal Dutch Medical Association made a distinction between 'informal discussion' between doctors and 'formal consultation'. The latter was argued to be one of the necessary procedural preconditions in the case of euthanasia. Thirdly, also of significance was the 1985 report of the State Commission on Euthanasia. The Commission was installed in 1982 to advise on future Dutch policy concerning euthanasia, especially focusing on matters of legislation and implementation. In its report, the commission formulated four requirements for legal euthanasia,

5 For further details on the case of *Mia Versluis*, who was a young woman in coma following cardiac arrest during an operation, see Griffiths, J., Bood, A., and Weyers, H., *Euthanasia and Law in the Netherlands*, Amsterdam, Amsterdam University Press (1998) 47-48.

6 Actually because of formal procedural rules in medical disciplinary law, he himself was not allowed to appeal; this was done by the medical inspector who acted as a plaintiff on his behalf.

7 However, the doctor was convicted of behaviour that undermines public confidence in the medical profession. He was required to pay a fine of Hfl.1,000 and the verdict was ordered to be published in the *Official Gazette*. Both are considered relatively heavy sanctions in Dutch medical disciplinary law.

8 *NJ* 1982, no. 63: 223. Ms. Wertheim, who was not a doctor, was prosecuted for having assisted the suicide of a 67-year old woman who suffered from many ailments and had many times expressed her wish to die.

9 See in Griffiths, J., Bood, A. and Weyers, H., *Euthanasia and Law in the Netherlands*, above, 59.

10 However, the courts have not treated consultation as an absolute requirement. Given certain circumstances, not consulting does not preclude the defense of necessity.

the last of which reads: 'the doctor must consult with a doctor designated by the Minister of Health'.¹¹

The consultation requirement was subsequently embodied in the requirements of careful practice as formulated in the 1990 agreement between the Committee of Procurators-General and the Dutch Medical Association.¹² The requirement has been retained in the Termination of Life on Request Law.

In order to assess compliance with the requirement, two preliminary issues must be addressed. First, what precisely does the requirement entail? Second, what purposes is consultation supposed to serve?

Concerning the first question, the rules are clear. In effect three conditions must be fulfilled. The colleague must be independent, i.e. not a subordinate, nor a fellow-member of a joint practice, nor a colleague in a group practice of specialists, nor a doctor involved in the treatment of the patient. The consultant must assess whether the patient's request is voluntary, well considered and persistent. In addition he has to check the medical condition and the life-expectancy of the patient as well as the availability of alternative (for instance: palliative) treatment options. Finally, the consultant must make a written report of his findings. It is important to note that irrespective of the consultant's opinion, it is always the consulting doctor who is equally responsible for euthanasia.¹³

As to the second question, there is considerably less agreement concerning the purpose of consultation. In the most recent and comprehensive study of the issue, the author nowhere explicitly deals with this matter.¹⁴ According to my reading of the literature, two different functions of consultation in relation to euthanasia are distinguished: a medical and a legal one.¹⁵ The medical function can be described as the reduction of uncertainty for the doctor handling a case as regards the medical situation and possible treatment. A 'second opinion' is normal in medical practice – outside the realm of medical behaviour that potentially shortens life – and is seen as a way of reducing uncertainty due to incom-

11 The Commission proposed that the Minister of Health appoint a limited number of doctors, paid by the Government, to serve as consultants. The proposal never became effective and doctors are still able to make their own free choice of consultant. However, as we will see, the basic element of this proposal, i.e. a group of doctors specially trained to act as consultants, was to re-emerge in Dutch euthanasia practice some ten years later in the form of a local experiment in the city of Amsterdam initiated by the Medical Association.

12 This committee, which consists of five PGs, is the prosecutorial authority. Since 1985 this Committee has been in charge of making all final decisions as to whether or not to prosecute cases of euthanasia.

13 However, it is unclear what the rule is if the consultant advises against euthanasia.

14 Onwuteaka-Philipsen, B., *Consultation of another physician in cases of euthanasia and physician-assisted suicide*, Amsterdam, (1999).

15 See Sutorius, E., 'Een antwoord op euthanasie vanuit het recht', in: Kuitert, H. M., 'Verantwoorde levensbeëindiging?: medische, ethische en juridische aspecten', Delft; Meyboom-de Jong, B., 'Second opinion bij euthanasie: meer macht voor de patiënt', (1994) 37, *Huisarts en Wetenschap*, 461-463; Kimsma, G. K., 'Objectivering van de zorgvuldigheidseisen: mogelijkheden en problemen' in: *Levensbeëindigend handelen door een arts: tussen norm en praktijk*, Legemaate, J., en Dillmann, R. J. M. (eds), Houten/Diegem, Bohn Stafleu Van Loghum (1998), 85-114.

plete knowledge. The legal function focuses on the accountability of the medical professional. This function has been described most explicitly by Griffiths, who believes that 'the principal function of consultation is not the *'second opinion'* but rather *'control'*: that another (expert) person knows what the situation was before the patient died'.¹⁶ The same idea has been put forward by Leenen, who observes that consultation was originally meant to guarantee careful medical decision-making (considered necessary because of the irreversible character of euthanasia) but that in the course of the development of euthanasia practice it has gradually evolved into a restraint on prosecutorial discretion of the Public Prosecutor and as a consequence serves to free doctors from criminal prosecution.¹⁷ Both authors seem to agree that consultation can be considered a form of *a priori* legal control, supplementing and supporting reporting as a form of legal control *a posteriori*.

2.2 The reporting requirement

The Burial and Cremation Act (1956) requires a doctor's declaration that a person's death was due to natural causes before the city clerk can give permission for the funeral or cremation. If the doctor is not able to provide the declaration, he must abstain from filing the requested certificate and must report the death to the municipal coroner. The coroner examines the body and makes his own assessment of the cause of death. If the coroner decides that the death is not a natural one, he must inform the local prosecutor.

Application of this legal regime in the case of euthanasia depends on whether or not such a death can be considered a natural one. The position of the Royal Dutch Medical Association (KNMG) has always been quite consistent. As early as 1973 the Association released a report of a special working group – *A provisional viewpoint on euthanasia* – which stated that in the case of euthanasia, a doctor must not file a certificate of natural death. One may conclude from the 1982 Health Council Report to the Government, that many doctors were ignoring the legal rule. The Council observed that doctors sometimes had 'reasons of a practical nature' for submitting a certificate of natural death, since a criminal investigation imposed a heavy burden on both the doctor and the patient's family. In 1985 the State Commission on Euthanasia took a firm stand and proposed a specific criminal offence for a doctor who files a natural death

16 See, Griffiths, J., Bood, A. and Weyers, H., *Euthanasia and Law in the Netherlands*, above, 90, footnote 2 (emphasis added, AK). Griffiths quotes from a personal letter from Josephus Jitta, a former local prosecutor in the district of Alkmaar, who in 1985 carried out some informal 'field-experiment' creating a specific reporting procedure in his district and promised doctors that they would not encounter difficulties with the law if they report euthanasia in stead of filing a 'natural death'-certificate. On the basis of his wide experience Josephus Jitta argues that the medical aspects of euthanasia seldom or never give cause to doubt; in his view consultation serves primarily non-medical goals (for instance, making certain that the request is voluntary and well-considered).

17 See Leenen, H.J.J., 'Toetsing van euthanasie: de impuls van SCEA', (2000) *Medisch Contact*, 1090.

certificate after performing euthanasia. Finally, the Medical Association in its 1998 report – *Viewpoint on Euthanasia* – took notice of recent publications that suggested it was common practice among doctors to file a natural death certificate in cases of euthanasia, but condemned such a practice and called on doctors to make an end to it. The issue was settled by the Dutch Supreme Court, which ruled in 1987 that a doctor filing a natural death certificate in the case of euthanasia was guilty of fraud.

In the Autumn of 1990 the Minister of Justice announced a special procedure for reporting euthanasia. This procedure had been arrived at in negotiations between the Medical Association and the Committee of Procurators-General.¹⁸ The resulting 'ministerial agreement' stated that if a doctor reported properly, the prosecutor's investigation would be as discrete as possible in order not to aggravate the situation for the doctor as well as the patient's family. This agreement subsequently obtained a more formal legal status in 1994, in an amendment to section 10 of the Burial and Cremation Act.¹⁹ This special reporting procedure for euthanasia that emerged in this way has been incorporated in the recently adopted Law Termination of Life on Request.

In November 1998 the Government introduced an important change in the procedure. Five Regional Assessment Committees were established, each consisting of a lawyer (chair), an ethicist and a doctor, appointed by the Ministers of Justice and Health. A doctor's report of euthanasia was henceforth to be assessed in the first instance by one of these committees.²⁰ The committees, which are in essence a non criminal legal enforcement agencies must assess to what degree the behaviour of the doctor meets the requirements of careful practice.²¹

The committees were to advise the prosecutorial authorities on whether or not to take further steps and it would be prosecutorial policy to deviate from such an advice only in exceptional circumstances. The committees were meant to function as a 'buffer' between the doctor and the criminal law. This was ex-

18 The Association had argued that such a procedure was a necessary precondition for doctors to be willing to participate to the first national empirical study on euthanasia. This research was commissioned by the Ministers of Justice and Health as part of the deal made during the 1989 formation of a new Government (by the Christian Democrats and the Labor Party): the parties agreed that further legislative steps should await the results of such a national study.

19 This section reads: 'If the coroner is of the opinion that he cannot issue a death certificate, he shall without delay report to the prosecutor by means of a form prescribed by Order in Council. The Order in Council referred to in the previous sentence is to be submitted for approval by Our Minister of Justice and Our Minister of Health'. For further details, see Griffiths, J., Bood, A. and Weyers, H., *Euthanasia and Law in the Netherlands*, above, 309. The Order in Council pursuant to article 10 was issued on December 17 1993 and became effective June 1 1994. In due course I will come back to this Order in Council.

20 To be more specific: in effect doctors do not report directly to these committees nor did they to the (local) prosecutor. They have to inform the coroner who send the official documents to the relevant authority.

21 In effect the concept of such committees was already formulated in the 1984 report of the Medical Association. But at that time their role, however, was thought to be different: i.e., to provide the doctors some kind of a judgement before he was entitled to perform euthanasia. In this way, the committees would function as an *a priori* control instead of the *a posteriori* form of legal control as is now the case.

pected to increase the willingness of doctors to report. Furthermore, through direct, professional exchanges with doctors, the committees would contribute to the improvement of medical-professional decision-making in euthanasia practice. The committees were required to report annually to both the Ministers of Justice and Health, on, among other things, the number of cases reported to them as well as on the way they dealt with these cases. These reports were also supposed to contribute to the improvement of the decision-making process.

The recently adopted Law on Termination of Life on Request, which comes into effect in the Spring of 2002, makes important changes in the authority of these committees. Under the new regime, a committee will no longer have to pass every case known to it, on to the prosecutorial authorities, accompanied by the committee's advice. Only cases where, in the committee's opinion, the doctor has not complied with the 'requirements of careful practice' are to be handed over to the prosecutorial authorities. It is assumed that this change will strengthen the 'buffer function' of the committees and hence increase the willingness of doctors to report.

The legal requirement to report cases of euthanasia as such is considered in the Netherlands the cornerstone of the formal accountability that is an essential condition of the social acceptability of the practice. It is accountability that enables us to entrust such a precarious practice to doctors.

3. Medical Practice: Law in Action

So far, the requirements of careful practice have been discussed from a legal-normative perspective. The focus has been on the rules that have been created, their goals and how they are to be interpreted. Let us now turn to what is known about actual practice from the available empirical data.

3.1 *The consultation requirement in practice*

There is too little known about consultation during the nineteen seventies and early eighties to permit more than a few impressionistic generalisations. From the few data available, one may safely conclude that consultation at that time was far from common practice. Based on the small-scale research he carried out in the early eighties, Hilhorst noted that clearly-defined decision-making procedures for euthanasia were essentially non-existent among GPs.²² Hilhorst's finding is corroborated by Spreeuwenberg, a leading figure within the Medical Association and a member of the Association's committee that wrote the 1984 report. At that time he was a professor of general practitioner medicine. He was recently interviewed by Weyers on the emergence of the consultation norm as

22 Hilhorst as cited in Griffiths, J., Bood, A. and Weyers, H., *Euthanasia and Law in the Netherlands*, above, 57.

formulated in the 1985 Association's-report.²³ In view of the increasing importance given in medical practice to notions such as 'peer-review' and the like, as instrumental to the quality of care in medical practice, he began to promote consultation in his teachings. Being a member of the committee formulating the criteria that doctors would have to meet in order to carry out euthanasia in a medically proper way, it was obvious to him that consultation should be among them. Such a statement would be hard to understand if consultation had already become routine in the euthanasia practice of GPs. Finally, unpublished research used as evidence by the defence lawyer in the *Pols* case (1984) supports the same conclusion.²⁴ This research reported on the practices of four GPs who in total had carried out euthanasia at least 18 times during the previous three or four years. In only two of these cases had consultation with a colleague taken place.

The first research to provide us with some general, national data, on the frequency of consultation among GPs in their practice of euthanasia was conducted by Van der Wal.²⁵ Covering the period 1986-1990, the author concluded that in 75% of the relevant cases doctors had consulted a second doctor. This figure suggests that the Medical Association may have been successful in taking a firm stand on the necessity of consultation. Further corroboration came from the national survey conducted by Van der Wal and Van der Maas in 1995, which found a consultation rate by GPs of 78%.²⁶ According to these authors, nothing seemed to have changed with respect to the frequency of consultation in the years between 1990-1995, but a great deal appeared to have changed with regard to the quality of consultation: the professional character of consultation, the independence of the consultants, their expertise, their reports and the way doctors dealt with the consultants' opinions had all improved.

Nevertheless, there was still some cause for concern over the quality of consultation. Because of this the Medical Association showed a keen interest in an experiment initiated by the Amsterdam Association of GPs in 1997. In this experiment, called '*Support and Consultation on Euthanasia in Amsterdam*' (abbreviated in Dutch: SCEA), some 20 trained GPs were made available on a

23 Personal communication from Weyers.

24 In this case of a psychiatrist, who had reported her case but who had not consulted with colleagues before carrying out euthanasia, the Court of Appeals rejected the defence of necessity because Ms Pols should have consulted since, among other things, she had ties of friendship with the deceased. See Griffiths, J., Bood, A. and Weyers, H., *Euthanasia and Law in the Netherlands*, above, 64.

25 Wal, G. van der, *Euthanasie en hulp bij zelfdoding door huisartsen*, Rotterdam, WYT Uitgeefgroep, (1991) 39-48 [40]. This study was based on a postal survey among two random samples; one taken from GPs in the province of North Holland (n= 521; nearly half the total GP population) and one taken from GPs in the rest of the Netherlands (n=521; 10% of the GP population in the other provinces).

26 Wal, G. van der, and Maas, P.J. van der, *Euthanasie en andere medische beslissingen rond het levenseinde*, Den Haag, SdU Uitgevers, (1996) 109. This study encompasses several sub-studies, among them an interview study and a death certificate study. The consultation percentage given stems from the interview study; the death certificate study comes up with a lower level of consultation: 63%.

daily duty-scheme basis to doctors to provide them with both general advice on euthanasia and to act as consultants as specified in the requirements of careful practice. The project ran on an experimental basis for one year, after which it was evaluated by Onwuteaka-Philipsen and Van der Wal.²⁷ The goals of the project were threefold: (1) to support GPs and improve the quality of consultation, (2) to improve the professionalism of medical decision-making and of the performance of euthanasia, and (3) to increase the willingness of doctors to report cases of euthanasia.²⁸ Because the experiment was deemed to be a success, the Minister of Health decided to continue and even to enlarge the governmental subsidy in order to become SCEA a nation-wide experimental project – ‘*Support and Consultation on Euthanasia in the Netherlands*’ (SCEN).

The creation of the Regional Assessment Committees can also be regarded as a contribution to the quality of consultation, since one of the principal purposes of these committees is – by providing feedback to doctors and in other ways – to improve the quality of euthanasia practice and, in particular, the level of adherence to the ‘requirements of careful practice’.

3.2 The reporting requirement in practice

The first national study on medical practice concerning the end of life, conducted by Van der Maas in 1991, addressed itself in particular to the frequency of euthanasia.²⁹ There are no reliable data on frequencies for earlier years, but some small scale studies give estimates between 3,000 and 5,000.³⁰ Van der Maas’ study shows that the actual frequency in 1990 was about 2,700 per year. While sheer numbers are of some interest on their own, to us their main importance is in providing a baseline to be used in calculating the rate at which doctors in fact report cases of euthanasia. Van der Maas tried to estimate that rate: relating the total number of cases in the survey that doctors said they had reported to the total number of euthanasia cases they mentioned, he came up with a reporting rate of 22% at that time.³¹

27 See Onwuteaka-Philipsen, B. & Van der Wal, G., *Steun en consultatie bij euthanasie in Amsterdam*, Amsterdam, Vrije Universiteit Amsterdam, (1998).

28 There is some confusion whether the third goal should be seen as goal of SCEA or only as a desired side effect. I leave this question aside, noting only that SCEA did not in fact have such an effect.

29 Maas, P. van der, Delden J. van, and Pijnenborg L., *Euthanasia and Other Medical Decisions Concerning the End of Life: An Investigation Performed Upon Request of the Commission of Inquiry into the Medical Practice Concerning Euthanasia*, Health Policy Monographs, Vol. 2, Amsterdam, 1992. The original Dutch report was published in 1991. The study encompassed several sub studies among them an interview study. I rely on the findings of their interview study.

30 Van der Werff (1986) – as cited in Griffiths, J., Bood, A. and Weyers, H., *Euthanasia and Law in the Netherlands*, above, 202 – mentions much higher estimates. The authors however point to conceptual vagueness of the term ‘euthanasia’ used during these days, which probably explains the higher numbers.

31 Van der Wal, based on his research covering the period 1986-1990, found a reporting rate of 26% in his national sample, while the reporting rate among the GPs from the province of

Four years later Van der Wal and Van der Maas replicated (to a large extent) the 1990 study. Using the same methods, the authors estimated the total number of euthanasia cases in 1995 to be 3,600. They calculated the reporting rate, however, in a methodologically better way: relating the total number of cases in fact reported to the authorities to the total number of euthanasia cases mentioned by doctors in answering the survey. This produced a 1995 reporting rate of 41%, which they were able to compare to the 1990 which, calculated in the same way, was 18%.³²

Although the researchers themselves considered the increase in the reporting rate 'substantial', their findings inflamed the political debate. There was a general consensus that the level of reporting was much too low and that the reporting procedure was therefore ineffective. Thus the question arose as to how the control system could be improved: i.e., how to motivate doctors to report cases of euthanasia. Possible answers to this question seemed to be provided by other findings of the research dealing with the motives of doctors for not reporting and their preferences for changes in the reporting procedure. If one reads doctors' answers to questions concerning their reasons for not reporting as reflecting a cost/benefit, then one arrives at a rather clear picture.³³ Most of those who reported (75%) stated that reporting was in agreement with their own standards. A rather small percentage of answers mentioned external constraints, such as the policy of the institution where they worked (13%) and the risk of getting into 'legal difficulty' (7%). However, those who had *not* reported justified their behaviour predominantly by pointing to the high costs that reporting entails: the bureaucratic hassle and unpleasantness of the procedure itself (for themselves as well as for the family of the deceased) (30%-55%), and fear of legal difficulties, including criminal prosecution (36%). As far as doctors' preferences for the authority most suitable for assessing their behaviour is concerned, a distinction must be made between the legal control *a priori* and *a posteriori*. As to the former, four out of five GPs opted for medical-professional control. There was less unanimity concerning control *a posteriori*, but six out of ten GPs would prefer a non-criminal body in which members of their profession would, to some extent, be included.³⁴

In response to those findings, the Government decided to make an important change in the structure of the reporting procedure. As mentioned earlier, in late 1998 multi-disciplinary, non-criminal assessment committees were established in order to make a first assessment of reported cases. One can interpret the reasoning behind this change as a strategy implying a twofold reduction in the perceived costs of reporting. First, a less direct exposure of a reporting doctor

Noth-Holland was 32%. However, the difference proved not to be statistically significant. Van der Wal, G., *Euthanasie en hulp bij zelfdoding door huisartsen*, above, 103.

32 In 1990, 484 cases of euthanasia were reported to the prosecutor; 2,700 cases of euthanasia were (self) reported by the doctors in the survey. For 1995, these figures are respectively: 1,463 and 3,600 (see Wal, G. van der, and Maas, P.J. van der, *Euthanasie en andere beslissingen rond het levenseinde*, above, 110).

33 *Ibid.*, 118-121.

34 *Ibid.*, 163.

to the criminal law and second, the introduction of a less purely 'legal' assessment more congenial to doctors. The first two annual reports published by the committees suggest, at first glance, that doctors have reacted as they were expected to do. In 1999, 2,216 cases of euthanasia were reported, compared to 1,679 cases in 1996 and 1,927 cases in 1997. However, the number of cases reported in 2000 declined slightly to 2,213.³⁵

However, these figures do not tell us anything about the reporting *rate*, which is what we are interested in, in order to be able to assess the eventual effects of the policy adopted by the Government. For that we need to relate the number of reported cases to the total number of cases of euthanasia carried out each year. But since the latter figure is only available for the years 1990 and 1995 (when the national surveys among doctors were carried out) and extrapolating them would result in rather unreliable figures, one finds oneself in a serious dilemma.

Fortunately, another approach is available which enables us to evaluate the success of the new reporting procedure even though we do not have exact data on the rate of euthanasia.

4. An Alternative Approach to Policy Evaluation

Policy evaluation research must focus on three questions: first, a description of what the implementation of the policy under study actually entailed, especially at the shop-floor where effects on the behaviour of individual doctors were expected; second, a description of actual changes in the regulated behaviour, and third, an explanation of these behavioural changes in terms of reactions of the actors concerned to the policy intervention as implemented. In evaluating Dutch euthanasia policy one must consider the degree to which medical practice is in agreement with the rules of the level of daily medical practice, and what mechanisms might account for the observed behaviour. As to actual behaviour, both the 1990 and the 1995 studies are exemplary in their design, providing us with a great richness of descriptive data on medical practice.³⁶ Un-

35 The Dutch political reaction to these figures was peculiar. Even before the first Annual Report of the Five Regional Committees was released (in May 2000) some commentators judged the assessment committees to be a failure because the numbers reported did not seem to increase. This debate was fueled to some extent by the fact that the sheer number of reported cases over 1998 seemed to be 2,590 which would have implied that the numbers over the year 1999 had dramatically declined. See Klijn, A and Griffiths, J., 'De regionale toetsingscommissies en de ontwikkeling van de meldingsfrequentie euthanasie', (2000) 30, *Nederlands Juristenblad*, 1486-1489. Only very recently has it been discovered that the 1998 figure was based on misinformation given by the Public Prosecutors' Office. See Klijn, A., 'De meldingsfrequentie euthanasie opnieuw', (forthcoming).

36 It is for this reason that their research design has been replicated by researchers in other countries such as Australia (see Kuhse, H., *et al.*, 'End-of-life decisions in Australian Medical Practice', (1997) 166 *Medical Journal of Australia*, 191-196) and Belgium (see Deliens, L., *et al.*, 'End-of-life Decisions in Medical Practice in Flanders, Belgium: a Nationwide Survey', (2000) 356, *The Lancet*, 1806-1812) and also in the current European Comparative Project. See Heide, A. van der, *et al.*, 'End-of-life decisions in Six European Countries', in this Issue.

fortunately, with regard to both implementation and to explanation, the studies fall short, not even mentioning these key aspects of evaluation. Thus, it is not clear from their research whether various policy interventions during the last decade have actually influenced the choices of doctors whether to report or not. When the researchers discovered that the 1995 reporting rate was higher than that of 1990, they simply concluded that this was caused by the purely formal legislative change in 1994 to the reporting procedure that had been in effect since 1990. As I will argue, however, the 1994 law probably had no such effect.

4.1 *The reporting frequency reconceptualised*

In order to go beyond the *post-hoc, propter-hoc* reasoning of the 1995 study, I would like to propose another way of estimating the changes in reporting behaviour during the last decade, based on annual data that we can rely on. It is possible to construct a yearly rate by relating the total number of euthanasia cases reported to the authorities to the total number of deaths as published by the Central Bureau of Statistics. Given the assumption that the proportion of deaths attributable to euthanasia has been rather stable over the recent years, one can interpret an increase as indicating an increased rate of reporting.

Before sketching the pattern of reporting during the last decade, it may be useful to anticipate and address some of the objections that can be made against the proposed method.

First, one could argue that the assumption of the stability of the proportion of euthanasia cases to total annual deaths seems rather dubious since the incidence of euthanasia may well be increasing significantly as euthanasia becomes more 'normal' and generally accepted. But this is not the case. In effect, over the years 1990-1995 there seems to have been hardly any increase in the proportion of euthanasia to all deaths. The researches argued that the absolute growth in euthanasia from 1990 to 1995 can only partly be attributed to the increasing role of cancer as a cause of death. In addition, part of the explanation lies in the increased willingness of doctors to admit to themselves a 'heavier' intent when administering lethal drugs. If this is true, it would mean a change in definition of the situation, which is of course not the same as an actual increase in the euthanasia share itself.³⁷ It is also interesting to note the reasoning by Van der Wal some years later, with reference to the increase in the number of reported cases in 1996 and 1997 as compared to 1995. Van der Wal argued that the increase in reporting was not due to an increase in the frequency of euthanasia, which he believed had found its maximum.³⁸

Another objection to my assumption might read: the rate of euthanasia has been increased because doctors become more willing to perform euthanasia.

37 Wal, G van der, and Maas, P.J. van der, *Euthanasie en andere beslissingen rond het levens-einde*, above, 94.

38 See 'Artsen wennen aan melden euthanasie', *NRC/Handelsblad*, August 7, 1998.

Other authors in this Issue who are dealing with this 'slippery-slope'-like reasoning show the empirical weakness of that objection.³⁹

One might argue in the opposite direction, pointing to the increasing attention paid to palliative care which some people suppose will reduce the rate of euthanasia. If that were the case, my method of estimating the reporting rate might, indeed, significantly overestimate the euthanasia frequency (and by consequence, underestimate of the reporting rate).

A final objection that might be made to my proposed method of estimating the reporting rate, is that using unqualified death figures overlooks the yearly variation in the causes of death. Since the chance of euthanasia occurring differs for different causes of death and there is a rather substantial variation in these causes over the years, the result of my method might be distorted by changes in the baseline.⁴⁰ However, death rates corrected for this effect hardly differ from the uncorrected rates. This means that the objection – luckily – appears to have little weight. All in all, in my opinion there is no reason to reject the assumption made here that the proportion of euthanasia deaths in the total number of deaths has been rather stable during the 1980s and the 1990s.

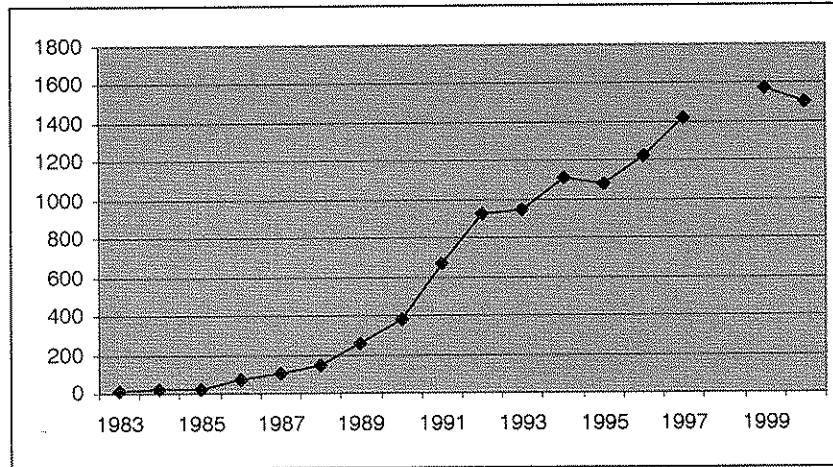
Whatever the merit might be of these various objections, the problem of (under)estimating the number of euthanasia cases is not unique to my method; it is also inherent in the way Van der Wal and Van der Maas proceeded in their estimation of the reporting rate. This is because of the fact, as Griffiths has argued, counting the numbers of euthanasia cases is not like counting the number of deaths. In effect one counts the number of situations doctors are willing to define as euthanasia. 'The problem is not just that a doctor can describe the same sort of behaviour in different terms, but that he can choose different ways of accomplishing the same result. In effect, he 'constructs' the patient's death. By this we mean: he behaves in a way that permits a certain description'.⁴¹

In applying the method as suggested, one can sketch the development in reporting rates over a period of nearly twenty years, with the exception of 1998 (due to unreliability of the data on the number of reported euthanasia cases in that year provided by the Public Prosecutor's Office).

39 See Schwitters, R.J.S., 'Slipping into Normality?' and Otłowski, M., 'The Effectiveness of Legal Control of Euthanasia' in this Issue.

40 See Wal, G. van der, and Maas, P.J. van der, *Euthanasie en andere beslissingen rond het levenseinde*, above, 54 tabel 5.4. From this one can conclude, for example, that the euthanasia chance in case of death caused by cancer (78/27: 2.8) is as three times as high as in case of death due to mental-disease (6/11: 0.54). My calculations concerning the chance of euthanasia is based on the given share for euthanasia and not that of assisted suicide.

41 See Griffiths, J., Bood, A. and Weyers, H., *Euthanasia and Law in the Netherlands*, above, 254.

Figure 1. Frequency of Reporting Cases of Euthanasia, 1983 – 2000

(per 100,000 deaths)

The curve as presented shows three things. First, generally speaking, there has been a quite remarkable and consistent growth in the reporting rate over the last decade, especially in the early 1990s and in the years after 1995. Second, in contrast to the impression one would get by looking only at the sheer numbers of reported cases, there seems to have been a stagnation in the upward trend of reporting during the last two years. And finally, there seems to have been a small period of comparable stagnation in the years 1993-1995. The question I want to address is: how can the reporting pattern as a whole – the rapid growth and the periods of stagnation – be explained?

4.2 The presumed answer: legal insecurity

In answering this question, one has to consider that a doctor who carries out euthanasia finds himself in a precarious position. He will be criminally liable unless he behaves in accordance with the 'requirements of careful practice'. These rules put some restraints on his behavioural options. It seems reasonable to assume that a doctor will usually opt for the choice that is most likely to enhance his own peace of mind and to give him as much freedom as possible from external control including all the unpleasant consequences that may follow from following or not following existing rules. In making his choice, the doctor must balance three different types of consideration. On the ethical-professional level, he may, perhaps, find consultation and reporting not in agreement with his personal conviction that euthanasia, like medical treatment in general, is a private matter. But the 'requirements of careful practice' are endorsed by the Royal Dutch Medical Association and behaving inconsistently with them would put

such a doctor in a state of normative dissonance. On a practical level, going by the rules saddles the doctor with a fairly substantial amount of extra work. And there is the risk of getting into 'legal difficulties', be it from medical disciplinary law or prosecutorial officials. The alternative approach of neglecting the rules may entail only a small risk of being caught, but it does have other costs, moral as well as practical, in particular the need to act secretly.

Here I will concentrate on the legal considerations because, as I will argue, the changes in the reporting procedure over the last decade can best be understood as a deliberate change in the conditions doctors must take account of when making a choice of whether to report or consult or not. Because the risk of being prosecuted has been reduced by providing clear rules doctors can rely on, the costs of reporting have decreased markedly.

The 1990 agreement between the prosecutorial authorities and the Medical Association substantially increased the legal security of a doctor who carries out euthanasia. The way this 'gentleman's agreement' was described by the Board of the Medical Association to the profession at large in the Association's weekly journal (*Medisch Contact*) underscores my thesis: '*An end to long-standing insecurity*'.⁴² It should follow from such a change that doctors would be more willing to report. Given increased security from clear rules and predictable behaviour of the control authorities, a doctor will consider himself able to estimate in advance his prospects of performing and reporting euthanasia without encountering legal difficulties. The greater the perceived probability of avoiding legal difficulties, the higher the reporting rate. As figure 1 shows, the increase in the rate of reporting during the years immediately after the 1990 agreement confirms this analysis.

But what then of the 1994 legislative ratification of the 1990 agreement? At first glance, one would be inclined to suppose such formalisation would have increased legal security for doctors. However, the Order in Council issued to implement the new Burial and Cremation Act had just the opposite effect. The Minister of Justice at the time was a Christian Democrat and intent upon restricting the practice of euthanasia to patients in the 'terminal phase' of their illness. Despite the lack of support for such a limitation in existing law, he insisted on including a new question on the form to be used for reporting euthanasia. That doctors were confused by this was reflected in the headline of a national newspaper: '*Euthanasia form disappoints doctors*'.⁴³ The Board of the Medical Association issued a statement to the effect that a decrease in the willingness of doctors to report was to be expected.

42 'Richtlijnen meldingsprocedure euthanasie en hulp bij zelfdoding', (1990) 44, *Medisch Contact*, 1303-1304. However, historically speaking, the suggestion of a radical change is not accurate. As we know from Weyers, the legal situation had changed as early as 1984. See Weyers, H., 'Euthanasia: The Process of Legal Change in the Netherlands', in this issue. But that change had not been perceived by doctors as a reduction of legal uncertainty.

43 *Volkskrant*, 23 December 1993.

Something similar took place in 1995. The then Minister of Justice, a Liberal Democrat, agreed with the position taken by the Dutch Association for Pediatrics as well as by a committee of the Medical Association, that under certain circumstances active termination of life in the case of new-born babies with serious defects can be justifiable.⁴⁴ She nevertheless ordered two doctors who had reported what they had done, to prosecute for murder, hoping that the courts would agree with her standpoint.

However different the policy goals of the two Ministers of Justice may have been, for doctors the consequences were the same: increased insecurity surrounding reporting. They reacted consistently by reporting less frequently in the years immediately following the ministerial actions, as we can see from figure 1.

I would argue that the same reasoning applies to the behaviour of doctors under the new control regime of the regional assessment committees. Although the new reporting procedure changed nothing in terms of the 'requirements of careful practice', the committees were new and their behaviour apparently seemed unpredictable to doctors. Even though the composition of the committees may seem more 'medical' and thus less threatening than prosecutorial authorities, the committees also involve more expert external control since the medical members can be supposed to know much better than a prosecutor what constitutes proper medical behaviour. As we know from the committees' annual reports, the committees behaved in the same way the prosecutors had done in previous years as far as their final judgements of the reporting doctors' behaviour. All cases reported to the committees in 1999 were found to have fulfilled the 'requirements of careful practice' and only three of the cases reported in 2000 were found to fall short.⁴⁵ One might thus be tempted to conclude that there were no grounds for doctors feeling less secure. On the other hand, the communication between the committees and reporting doctors was very different from that which had previously existed between prosecutors and reporting doctors. During the first year, for instance, 200 doctors – i.e., 10% of the total number of cases reported to the committees – were asked to provide further detail about their behaviour.⁴⁶ As we know from 'letters to the editor' in the Association's weekly journal (*Medisch Contact*), doctors expressed real fear of such hearings and requests, feeling themselves to be 'under examination'. One might, therefore, expect doctors again to react as they had before under conditions of increased legal insecurity: a decrease in their willingness to report.⁴⁷

44 Sorgdrager, W., and Eilers-Borst, E., 'Euthanasie: de stand van zaken', (1995), *Medisch Contact*, 381-384.

45 However, the Public Prosecutor decided to prosecute these doctors.

46 Only a very small number of them were asked to appear in person before the committees.

47 In their second Annual Report, the committees explicitly mention that although doctors are at first made nervous by a request for additional information, they came to accept and even, in retrospect, to appreciate it.

5.4 A precarious empirical test

To what extent is such an interpretation of changes in the reporting rate supported by the facts? In other words, does the insecurity-thesis offer a reliable basis for understanding the behaviour of doctors? In an effort to measure the degree of legal insecurity, the annual reports of the Public Prosecutor over the period 1985-1997 can be used to establish how often 'investigational steps' were taken in cases which were reported.⁴⁸ Every time a prosecutor initiates a criminal investigation against a doctor who reported a case of euthanasia, this suggests to other doctors that reporting may get one into difficulties with the law'. Table 1 presents an overview of prosecutorial reactions over the period 1983-2000.

Table 1: The number of 'investigational steps' taken by the Public Prosecutor in reported cases of euthanasia, 1983 – 2000

	Cases reported to the prosecutorial authorities	Number of Investigations by the Public Prosecutor
1983	10*	2
1984	19*	3
1985	31*	4
1986	84*	2
1987	126*	3
1988	184*	2
1989	338*	1
1990	486	0
1991	866	0
1992	1201	4
1993	1304	15
1994	1487	10
1995	1466	5
1996	1679	4
1997	1900	0
1998	n.a.	3
1999	2216	0
2000	2123	0

* The figures for reported cases in the years 1983-1989 are not reporting figures in the true sense (input to the prosecutorial authorities), but they indicate the number of cases the authorities dealt with (output).

From the early 1980s, only two or three reports a year led to such prosecutorial attention and during the early nineties the attention even dropped to zero. But then, rather suddenly, the attention rate increased: four investigations in 1992,

48 The concept of 'investigational steps' refers to the first steps in the formal procedure of criminal prosecution. Such steps lead to the final decision whether or not to start a criminal prosecution.

followed by an 'explosion' in 1993 and 1994. Thereafter the numbers dropped rapidly to an even lower level than before. Expressed in terms of insecurity: the growing certainty in the nineteen eighties, and especially from 1985 on, was suddenly disturbed in the period 1993-1995. From the discussion above, we know some of the reasons for this change.

The 'insecurity-thesis' as put forward here, would acquire important empirical support if changes in the rate of reporting could be predicted on the basis of changes in the amount of the prosecutorial attention.⁴⁹ We have tried to do this by means of a regression analysis over the years 1990-1997.⁵⁰ The underlying model with which the reporting frequency is estimated assumes that the frequency of reporting in any particular year is influenced by two factors. First, there is a growth trend: every year the number of reported cases is assumed to grow as a result of the increased acceptance of the norm requiring reporting. That is to say, the policy of the Government and the Medical Association of promoting reporting is assumed to have some effect on medical practice generally.⁵¹ Second, there is the effect of the behaviour of the Prosecutors Office. Every prosecutorial step is assumed to decrease doctors' willingness to report. We assume the time to lag to be one year, i.e., the negative effect will be visible in the year immediately following the year in which the prosecutorial step was taken. Given these two assumptions the model predicts a significant inhibition-effect: an increase of 1-4 prosecutorial steps over 1,000 reported cases in a particular year, causes a drop in the number of reported cases by almost 3% in the year thereafter.

Having predicted the reporting rate each year, we can compare the actually observed frequency of reporting with the predicted frequency. Figure 2 presents the results.

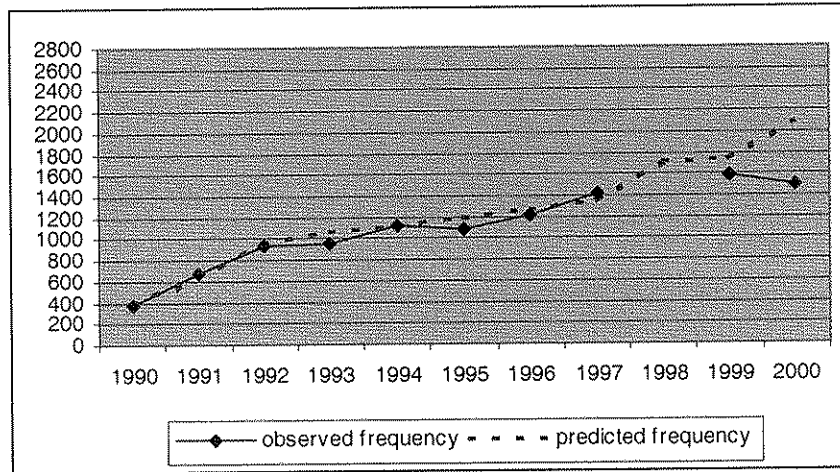
To the extent that the observed frequency of reporting conforms to the predicted frequency, the assumptions of the model are vindicated; doctors apparently seem to be able to take into account the inherent risk of reporting euthanasia. However, according to the 'insecurity-thesis', doctors are not able to do so any longer given *sudden* changes in the prosecutorial behaviour. Under such conditions we might expect the predicted frequency to deviate from the observed. One sees that in the years 1993-1995 the expected reporting frequency deviates from the observed frequency, indicating the effects of insecurity.

49 I would like to express my gratitude to my colleagues Frank van Tulder, who directed the following analysis methodologically as well as technically.

50 Use is made of an auto-regressive model of the first order. The year 1998 remains outside consideration because the Public Prosecutor's Office is unable to provide the number of reported cases.

51 In addition, it has to be noted that the model takes into account the existing level of reporting thus assuming a 'saturation-effect'.

Figure 2: Observed and Expected Frequency of Reporting Cases of Euthanasia, 1990- 200 (per 100,000 deaths)



Proceeding cautiously in view of the short period under study, we can similarly predict, the expected reporting frequency under the new reporting regime: for the years 1999 and 2000. A further increase in the frequency of reporting is predicted by the model, given the number of investigational steps for both these years. In fact, however, the reporting frequency has lagged markedly behind the prediction. The 'insecurity-thesis' developed above suggests that the explanation for this deviation may be attributable to another factor causing insecurity among doctors: i.e., the *new nature* of legal control.

6. Reflecting on the future

Having come this far in the analysis of the reporting frequency in the recent past, the obvious next question is: what will the future bring, in particular the new legal status the Regional Assessment Committees. Have received in the Law Termination of life on request.. Will this increase the reporting frequency as well as improve medical-professional decision-making? I believe that the above analysis indicates that, *ceteris paribus*, this indeed will be the case.

In his discussion of the social working of legal rules Griffiths emphasises the importance of the so called *general effects* of a legal rule.⁵² In contrast to its *specific effects*, i.e. the effects in cases in which the legal rule is applied to a specific case, the rule's general effects are its effects on the behaviour of people who anticipate the possible mobilisation of the rule by others. As Griffiths argues, as far as the effectiveness of a rule is concerned, its general effects are usually much more important than its specific effects. If a legal rule produces

⁵² See Griffiths, J., 'The social working of legal rules' (forthcoming).

the desired social consequences, this will almost always because people apply it to their own behaviour and those of others with whom they interact. If the rules governing euthanasia induce rule-conforming behaviour, this must take place at least a thousand times as often in cases that receives no prosecutorial attention as in prosecutorial cases.

Griffiths' reasoning also applies to the functioning of the assessment committees. The insecurity-thesis developed above predicts that to the extent the committees behave in a consistent and acceptable way, doctors will regain their ability to estimate the risk of reporting euthanasia. We therefore expect the reporting rate to return to a trend seen in the years before the establishment of the committees. In fact, we may even expect this rate to increase more sharply than in the past because of some specific insecurity-reducing aspects in the committees' functioning.

The committees' annual reports enable them to communicate to doctors in a much more direct and systematic way than the information that reached doctors the more or less haphazardly about criminal prosecution of individual doctors. The committees' Annual Report 2000, for example provides substantial insight in the reasoning behind the committees' assessments. In addition to general quantitative information, the report presents 14 reported cases. In each case the way the responsible committee came to its conclusion is discussed extensively. Not only is the feedback to doctors systematic, concrete and inclusive of all reported cases, the reasoning leading to the committees' decisions is communicated not just to the reporting doctors but to all doctors and the committees' comments are not limited to criticism of bad practice, but also emphasise that some doctors did particularly well. In short, the quality of the information given to doctors - the basis it affords them for knowing how to practice euthanasia and what the results of reporting are likely to be - is far better than in the case of control through criminal prosecution.

So far I have concentrated on the first policy goal: the increase in the reporting rate. But what about the second goal of the new committees: the improvement of medical decision-making? In closing my reflection on the immediate future, I want to dwell a moment on the issue of consultation.

In both the 1999 and the 2000 Annual Reports, the committees express their serious concern about the quality of consultation in euthanasia both with respect to the independence and to the quality of the written reports of the consultant. However, the committees make an exception in the case of consultation by the so-called 'SCEA consultants'. Not only are the SCEA-consultants 'independent' by definition (given the duty-scheme), the Annual Reports commend the written reports of these consultants for their completeness.⁵³ Such praise from the committees should be conceived to be an important, direct, stimulus to other doctors to improve their consultation behaviour.

53 See Onwuteaka-Philipsen, B.D. and Wal, G. van der, 'Consultatie bij euthanasie. Verslagen van SCEA-artsen en andere consulenten vergeleken', (2000) 33/34, *Medisch Contact*, 1201-1204.

But there is also an indirect stimulus with respect to the improvement of consultation behaviour. As we know from empirical research by Van der Wal among GPs, there is a correlation between consultation behaviour and reporting behaviour. Doctors who reported, had consulted much more often than those who had not. This proved to reflect a more general pattern. As the author concluded: 'if one complies with the reporting requirement, one also complies with respect to the other requirements of careful practice'.⁵⁴ The author interpreted this correlation in a more theoretical way, arguing that a doctor's intention to report a case of euthanasia leads him to anticipate in his behaviour on the wanted outcome: not getting into legal difficulties. Such a doctor will make sure that his consultation meets the legal requirements.⁵⁵

Some years later, Onwuteaka-Philipsen, in her research on the consultation behaviour of doctors, expressed the same idea when trying to explain her finding that although consultation frequency had not substantially changed during the years 1991-1995, the reporting frequency had. She noted: 'presumably the relationship between consultation and reporting is not reciprocal. A physician who intends to report a case will consult another physician, but a physician who does not intend to report a case does not necessarily refrain from consulting another physician when he feels a need for the opinion of a colleague'.⁵⁶ If she is right, we may cautiously infer from this that to the extent the assessment committees succeed in increasing doctors' willingness to report, they also will contribute to the improvement of the quality of consultation and thus medical decision-making at the end of life.

All in all, analysis of the developments in the behaviour of doctors seems to justify some cautious optimism concerning the immediate future with respect both to the reporting rate for euthanasia and the quality of consultation. Once some initial uncertainty among doctors has been overcome, the assessment committees should succeed in promoting the policy goal of increasing accountability to a much greater extent than is generally recognised in the current political debate.

Of course, the prediction may prove wrong. Firstly, because of empirical shortcomings in the data available for analysis. Secondly, because of theoretical flaws in my reasoning with regard to the 'insecurity-thesis' as an explanation for the reporting behaviour of doctors. Thirdly, because other factors may intervene and counteract the beneficial effects of the committees on the willingness of doctors to be accountable. For example: some current prosecutions in

54 See Wal, G. van der, *et al.*, 'De overlijdensverklaring en melding na euthanasie en hulp bij zelfdoding', (1992) 47, *Medisch Contact*, 43-47.

55 *Ibid.*, 47-48. Van der Wal argues: 'it may be that reporting invites a doctor to carry out euthanasia in a careful way, anticipating the possibility of legal assessment'. It might have been more precise if he had written 'the intention to report', because the reporting behaviour comes after the consultation and it seems rather odd to explain the behaviour *ex ante* by the behaviour *ex post*.

56 See Onwuteaka-Philipsen, B.D., *Consultation of another physician in cases of euthanasia and physician-assisted suicide*, above, 124.

rather controversial cases – although based on reports prior to the establishment of the assessment committees – may have such an unintended effect. We will only know for sure whether any such shortcomings have led to a wrong prediction, when new data are available. If so, new analyses will be necessary to explain changes in the reporting rate in a more satisfactory way. Better explanations, based on better insight in the behaviour of doctors, will then contribute to the accumulation of knowledge which is, in the end, the only lasting legitimization of our efforts.

The Prospects of Effective Legal Control on Euthanasia in Belgium

Implications of recent end-of-life studies

Freddy Mortier and Luc Deliens

1. Introduction

Following the Netherlands, Belgium will probably be the second country in the world to legalise euthanasia, defined as the intentional ending of another person's life, at that person's request.¹ A legislative proposal to that effect passed the Senate on 25 October 2001.² There appear, as yet, to be no obstacles to its final acceptance by the Chamber of Representatives. In addition to specifying the conditions under which euthanasia will not be prosecuted, this proposal also institutes a *a posteriori* procedure to evaluate whether these conditions were in fact met by the physicians involved. This procedure aims at protecting the patient's life, autonomy and well-being against non requested life-ending, undue external pressure, less than optimal curative or comfort treatment, technically inadequately performed euthanasia, and so on. The effectiveness of the law, as far as control is concerned, appears to depend primarily on the willingness of the physician to report cases where he assisted in dying to a federal commission and thus to expose himself to the risk of legal prosecution.³ Since rational actors try to avoid this risk, unless they are certain they have acted according to the requirements of the law, it may be hypothesised that the likelihood that euthanasia cases will be reported heavily depends on the conformity of the formal requirements of the law with the informal habits and rules already shaping daily medical practice. The more the current practices deviate from the normative aims embodied in the law, the less likely it is that euthanasia cases will be reported; the more the requirements are already respected, the more likely it is that effective control will be achieved.

Recently, our research team has collected epidemiological data for Flanders, the Dutch speaking sub-state of the Belgian federal state, on medical end-of-

1 The Belgium proposal only covers euthanasia, not assisted suicide. Although the Council of State recommended the inclusion of assisted suicide in the proposal, because of its similarity, in ethical terms, to euthanasia, the political majority left an eventual adaptation to the Chamber of Representatives (see Advice of the Council of State, dpc. 2-244/21 of the Belgian Senate, session 2000-2001, 2 July 2001). Therefore the following discussion focusses on euthanasia, although, as in the context of the Dutch debate, the two are often treated synonymously. When assisted suicide is included in the figures below for 'euthanasia', this will be clearly indicated.

2 For the history of the proposal see Adams, M., 'Euthanasia: the Process of Legal Change in Belgium', in this Issue.

3 A note on our terminology: 'he' is used to mean both 'he' and 'she'.

life practices and their carefulness. In addition, for one city, Hasselt, we also have at our disposal data on the attitudes of physicians that (partly) can explain their behaviour.⁴ In this paper, using these data, we will try to measure the width of the gap between the current practices and the legal norms laid down in the euthanasia legislative proposal. We will especially focus on the norm of respect for the patient's autonomy, probing a number of key questions: What is the current incidence of explicit patient requests in end-of-life decision making?; Why do physicians frequently omit to obtain that request?; What are the chances that a euthanasia law would alter physicians' behaviour in this respect?; and what, as a consequence, are the prospects of effective legal control of euthanasia?

2. Background

Articles 5-7 of the legislative proposal stipulate that the physician is obliged to report a euthanasia case within four days to a federal control and evaluation commission, consisting of eight physicians, four lawyers, and four members familiar with the problems of end-of-life care. The commission has to establish a two-part document.

The first part of the document is to be sealed by the physician. It is confidential and other than in exceptional circumstances, is not to form part of the commission's evaluation. It contains data identifying the patient, the treating physician, the physicians and all other people whom the treating physician consulted, and, where relevant, the representatives designated in the patient's living will.

The second part of the document contains demographic data of the patient; specifies the time and place of death; specifies the incurable pathology or accident suffered by the patient; explains the nature and causes of the unbearable, durable and non relievable suffering of the patient; specifies whether the patient's request was voluntary, taken without external pressure, well-considered and repeated; specifies whether the patient's death was expected to be imminent and whether there was a living will; lists the qualifications of the consulted physician(s), the content of their advice and the date of the consultation(s); and finally describes the way in which euthanasia was executed and the drugs that were used.

The commission has to examine whether the requirements of prudent practice were met solely on the basis of the second part of the document. Where the commission is in doubt about a particular case, it can decide, by a majority vote, to lift the anonymity of the case by opening the first part and to ask the physician for the complete medical file of the patient. When a majority of the commission judges that the requirements were not met, the case is sent to the public prosecutor for further legal action.

4 The research project in Hasselt was the pilot study for the Flanders-project on which this paper is based.

The evaluation and control procedure is meant to combine the authorisation to perform euthanasia with legal control. Although currently prohibited, according to physicians' self-reports, in about one out of twenty death cases in Flanders either euthanasia or non-explicitly requested life ending by the use of lethal drugs is involved.⁵ The frequency of this act contrasts with the virtual absence of legal control. Between 1980 and 2000 no cases of the use of lethal drugs have been brought to court and only a few cases have been investigated. Yet, since the legislative proposal has been debated, and probably because of this debate, four prosecutions have been undertaken. Two of these, one in the city of Antwerp and one in Tournai, involve the ending of a patient's life by nurses. Another one involves critical care physicians at a hospital in Liège. Very recently an inquiry was started into two cases of non-requested life ending by a specialist at a hospital in the city of Boom.⁶ Notably, the National Disciplinary Board of the Order of Physicians (which has judicial authority) is not eager to enforce its own prohibitive code on active life ending. Only in very few instances has a provincial Council of the Order of Physicians received a complaint about end-of-life practices or conducted (confidential) hearings about such cases. One case in 1963 is on record, involving the supply of lethal drugs to a grandmother, who used them to end the life of a defective new-born. Another complaint involved two Brussels physicians who ended the life of a patient without the patient's family's explicit request. The Boom-case mentioned above was, according to a newspaper, brought to the prosecutor's attention by the Order of Physicians.

Why would physicians who currently end their patients' lives by lethal drugs, and do so unpunished, take the risk of reporting such cases under the provisions of the new euthanasia law? Griffiths et al have convincingly argued that the likelihood that a system of criminal enforcement might by itself effectively control end-of-life practices are practically nil. Other types of enforcement, like professional pressures, are much more likely to succeed. In the Netherlands, medical disciplinary enforcement is already a much more powerful control mechanism than the criminal law.⁷ Accordingly, one might conjecture that once the new law authorising euthanasia is in effect, the medical profession itself will see to it that practices that are yet tolerated because the legal frame is outdated will be exposed to the public eye. Professional self-control would thus ensure compliance with the law.

The problem with this presumption is that the Belgium legislative proposal was not physician-initiated nor supported by the main medical associations. Although the content of the Belgian proposal is very similar to the Dutch law, the

5 Deliens, L., Mortier, F., Bilsen, J., Cosyns, M., Vander Stichele, R., Vanoverloop, J., and Ingels, K., 'End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey', (2000) 356, *Lancet*, 1806-1811.

6 *De Morgen*, 16.11.2001; *De Morgen* 30.11.2001.

7 See chapter 6 in Griffiths, J., Bood, A. and Weyers, H., *Euthanasia and Law in the Netherlands*, Amsterdam, Amsterdam University Press (1998).

social conditions under which both laws originated are very different.⁸ In the Netherlands, the 'requirements of careful practice' as stipulated by the Royal Dutch Medical Association (KNMG) in 1984, became the basis of the gradual clarification of the conditions under which euthanasia was not to be prosecuted. As Weyers extensively argues, the law on euthanasia that was adopted last April 2001, is a formalisation of rules proposed, recognised and applied by the physicians themselves.⁹ Belgium, on the other hand, has not experienced the long process of legal change and experimentation that the Netherlands went through. The main medical associations had no part in the development of the legislative proposal. From the point of view of many physicians, the euthanasia bill is thus a top-down affair, that exemplifies the intrusion of politics in medical practice.

The actual proposal has wide popular support, with three-quarters of the public approving of the legalisation of euthanasia.¹⁰ However, a questionnaire study sponsored by a medical newspaper, *De Artsenkrant*, shows that a significantly smaller proportion of about 42% of the Belgian physicians are prepared to practice euthanasia under some circumstances. Only 15% of all physicians are prepared to apply a law permitting euthanasia on a non-terminal incurable patient and an even smaller proportion of 12% regard the provisions of a living will requesting euthanasia as acceptable.¹¹ Most physicians, we may conclude, are adverse to euthanasia, and even more so, to some forms of euthanasia explicitly allowed by the legislative proposal. Of course, it is also the case that many individual physicians agree that euthanasia should be removed from the penal law.¹² The lack of support by medical associations is also apparent from the stipulations regarding end-of-life practices of the National Disciplinary Board of Physicians. As recently as 1992, the Board rewrote the chapter of the medical deontology code on euthanasia.¹³ Article 95 of the revised code states that the physician is not allowed to cause the death of a patient intentionally nor to help a patient to commit suicide. There is no sign that this article will be changed, although in 2000, a spokesman of the Board admitted orally that euthanasia might be justified in a situation of necessity.¹⁴

8 For further details see Adams, M., 'Euthanasia: the Process of Legal Change in Belgium', in this Issue.

9 See Weyers, H., 'Euthanasia: the Process of Legal Change in the Netherlands', in this Issue.

10 Several opinion polls and survey studies support this conclusion. For instance: A survey by INRA-Belgium published in *La libre Belgique* showed that 78% of the Belgian population have a positive attitude toward euthanasia: 77% in Flanders; 78% in Wallonia, and 82% in the city of Brussels. See <http://www.lalibre.be> (art. '72% de 'oui' à la proposition euthanasie').

11 *Artsenkrant – Journal du Médecin, Visie van de huisarts en geneesheer-specialist ten opzichte van euthanasie*. Leuven, Market Analysis & Synthesis (2001), 6-9.

12 A petition distributed in 2000 by the Dutch and French speaking Belgian Right-to-Die Societies obtained the signatures from 2,400 physicians.

13 Nationale Raad van de Orde van Geneesheren, *Code van geneeskundige plichtenleer*, aanpassing 1995, art. 95-98, 27.

14 The principle of informed consent, however, also at the end of the patient's life, is now explicitly accepted. In April 2000, art. 33 of the Medical Code was changed. It previously read that a serious prognosis may be hidden to the patient and that a fatal diagnosis may only be talked about very exceptionally and in a very cautious way. The new article obliges the physi-

Clearly, the prohibitive norms regarding end-of-life decision making officially shared by the members of the medical profession are outdated. As there is no other collectively enforced set of rules, the prospects of effective legal control therefore appear to depend on individual or perhaps on local-institutional codes that govern medical end-of-life practices. Using our empirical data, we will now sketch a picture of end-of-life decision making in Flanders and try to discern what may be the levers within the medical field for effective legal control.

3. Respect for Patients' Autonomy

3.1 Non-requested active life-ending

The requirements of careful practice formalised by the proposal are, among other things, meant to protect the patient against unrequested and against insufficiently clearly and explicitly requested life ending. The criterion whether the patient has or has not explicitly requested euthanasia is crucial for judging the acceptability of the use of lethal drugs. Many legal requirements of careful practice aim at establishing and evaluating the patient's wish to die. The absence of an established and valid wish makes life ending by lethal drugs illegal and this will remain so after the acceptance of the euthanasia legislative proposal. Although unrequested life ending may sometimes be justifiable from an ethical point of view, obviously the considerations applying in such cases are very different from those applying to euthanasia.¹⁵ To what degree, then, does medical practice at this moment deviate from the requirement of patient consent to or request for euthanasia? Table 1 provides some answers to this question, showing the incidence of end-of-life decisions in Flanders in 1998 and in the Netherlands in 1995. It appears that euthanasia occurs in Flanders in 1.1% of all death cases, non-explicitly requested life-ending by the use of lethal drugs occurs in 3.2% of all death cases.

Of course, one may accept that there are medical emergency situations in which unrequested life-ending is justified, for instance when a terminal patient is unable to communicate and his symptoms are refractory and exceedingly burdensome, painful, or degrading.¹⁶ However, without comparative data, it is hard to judge what would be the expected rate of such situations given the morbidity pattern of a population. The fact that the figure is four to five times higher in Flanders than in the neighbouring Netherlands supports the conclu-

cian to inform the patient, no matter how bad the prognosis. Yet, while informing, the physician must take into account the resilience of the patient and his willingness to be informed.

15 Wal, G. van der, 'Unrequested termination of life: is it permissible?', (1993) 7, *Bioethics*, 330-339.

16 For instance when a terminal patient is unable to communicate and his symptoms are refractory and exceedingly burdensome, painful, or degrading.

sion that the Belgian rate is unexpectedly high.¹⁷ Judging from the high rate of unrequested life termination in Belgium there is, at first sight, a huge gap between current medical practice and the normative aims of the euthanasia legislative proposal, so that the chances of achieving effective legal control seem to be slight. It should, however, be noted that the profile of the Dutch and Flemish patients dying without explicit request is very similar. In the Netherlands in 1995, for instance, 33% of these patients had a prognosis of less than 24 hours to live, and 58% was expected to die within one day to a week.¹⁸ The corresponding figures for Flanders are: 30% and 55%. In sum, the vast majority of these patients, in Belgium as well as in the Netherlands, was very near the end of their lives and received 'help in dying'.

Table 1. Estimated rate of end-of-life decisions in medical practice in Flanders and in the Netherlands*

	Flanders 1998	the Netherlands 1995
All deaths	56,354	135,546
Euthanasia	1.1 %	2.4%
Assisted suicide	0.1 %	0.2%
Termination of life		
without an explicit request	3.2 %	0.7%
Death potentially		
due to pain relief	18.5 %	19.1%
Death due to		
abstinence	16.4 %	20.2%
All deaths with an		
end-of-life decision	39.3 %	42.6%

* Table (modified) from Deliens, L., Mortier, F., Bilsen, J., Cosyns, M., Stichele, R. van der, Vanoverloop, J., Ingels, K., 'End-of-life decisions in medical practice in Flanders, Belgium: a nation-wide survey', (2000) 356, *Lancet*, 1806-1811.

The higher proportion of these patients in Belgium might then be explained by the lack of legal security offered to the parties involved in end-of-life decision-making, i.e. the patient, the family, the physician, and the nursing staff. Since euthanasia was still illegal in Belgium in 1998, the reasoning goes, patients refrained from asking the physician to shorten their survival. Conversely, the physicians were unlikely to take the initiative to get to know what the patient wanted. In a number of cases, the patient subsequently became incompetent and the communication delay ended in a communication stop. At this point, in

17 Another possibility is that the Dutch rate is unexpectedly low: this would mean that the Dutch physicians are not merciful enough and that they accept high levels of intolerable suffering in their patients. Generally, however, the figure of 0.7% of unrequested life termination is taken to show that the Dutch are either on a slippery slope or have been at the bottom from the very beginning. See Jochemsen, H. and Keown, J., 'Voluntary euthanasia under control? Further empirical evidence from the Netherlands', (1999) 25, *Journal of Medical Ethics*, 16-21; Fenigsen R, 'Dutch euthanasia revisited', (1997) 13, *Issues in Law and Medicine*, 301-11.

18 Cf. Deliens, L. *et al.*, 'End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey', above, 1806-1811.

about half of the cases of unrequested life termination (53%), the patient's relatives formulated an explicit request to end the patient's life. Only in about 18% of the cases was there no discussion with relatives, other physicians, or the nursing staff. Moreover, although in 38% of the cases, the patient formulated no explicit request to die, the matter had been previously discussed with the physician and eventually a general wish to die had been expressed by the patient. If this reasoning is correct, lifting the prohibition on euthanasia could by itself bridge the gap between current practice and the stipulations of the new law. Unfortunately, there is also evidence that the life and autonomy of patients are indeed badly protected in Belgium. The reasoning above, if valid, applies with regard to incompetent patients. But in only about 68% of the cases of unrequested life ending, the patient was, according to the physician's statement, indeed incompetent. In 20% of the cases, the physicians gave no information of the competency status of these patients, and in no less than 12% of the cases, according to the physician, the patient was competent when the decision was made to terminate his life. Within this group of competent patients there was a minority of 12% whose life was ended actively without a request formulated, a wish expressed or even a discussion with the physician. In the remainder of the cases (88%) there was either no information on other kinds of consent than the (lacking) explicit request or although there was no explicit request, some wish had previously been expressed or there had, at least, been a discussion with the physician.

3.2 'Non problematic' end-of-life decisions

When discussing the Belgian data, it is virtually impossible not to note the effect of the prohibition to use euthanatics, even at the patient's request. For instance, the Flemish death certificates offer information on the patient's professional occupation and level of education, making it possible to compute the association between the different types of end-of-life decisions and rough indicators of social class.¹⁹ The incidence of explicitly requested euthanasia is directly related to educational level, ranging from 0.5% for patients who only finished primary school to 3.8% for those who finished high school or college. The pattern for non-requested life termination, on the other hand, is socially irregular. It is practised most often on patients who did not finish high school (4.2%), least on those who only finished primary school (2.7%), with the better educated taking an in-between position (3.4%). When drugs are administered with the explicit intention to end life, the better educated are as likely to be given the drugs at request as they are to be given them without a request. The less educated are much more likely to die without a request than with a request.

Findings like these do not provide evidence that something is intrinsically wrong with the carefulness of the Flemish physicians. The observed inequali-

¹⁹ *Ibid.*

ties are partly caused by a prohibitive law. What happens, we may guess, is that the better-educated more frequently obtain what they want because they dare to ask it and have the ability to do so. The unequal protection afforded to the members of different social classes is thus likely to change, at least to a certain degree, with the legalisation of euthanasia. It could be argued that the same reasoning applies to the choice physicians have, in situations of necessity, between euthanasia and non-requested life ending. The overall incidence of the use of lethal drugs with the explicit intention to end the patient's life do not differ significantly between the Netherlands in 1995 and Flanders in 1998, but the Belgian physicians more often have recourse to non-requested life-ending than the Dutch physicians. The argument has been advanced repeatedly that the legalisation of euthanasia might actually prevent non-requested life ending, and so entail better protection of the patient's interests.²⁰ There is some evidence, however, that legalisation alone would offer insufficient protection.

This appears to be the case when other, so-called 'non-problematic' end-of-life decisions, are examined more closely. How well are the patient's interests against unrequested life ending protected when, for instance, treatment is withheld or withdrawn? Since non-treatment decisions are part of 'normal medical practice' in Belgium, the omission to discuss decisions with patients and to obtain their consent cannot, in these cases, be explained by the effect of a prohibitive law.

Non-treatment decisions intended to shorten the patient's survival

The overall proportion of non-treatment decisions amounts to 16.4% of all death cases (an estimated 9218 cases). In 6.7% of all death cases, the non-treatment decision was not explicitly intended to end the patient's life, but such was the explicit intention in 5.8% of all death cases, and there was a co-intention to terminate the patient's life in 3.9% of all death cases. In the cases in which the death of the patient was *somehow intended* (intended or co-intended), in 80% of the cases there was no discussion, nor a wish expressed, nor an indirect or earlier request by the patient. Within this non-consent group, a quarter of the patients was still competent.

Table 2 lists data for the whole of Flanders in 1998 and for the Flemish city of Hasselt. For comparison's sake, the corresponding figures for the Netherlands are also given. It appears that the proportion of cases in which there was no discussion at all with the patient are very high in Flanders and in Hasselt. Moreover, non-discussed non-treatment decisions were relatively often made on behalf of competent patients. In the Netherlands, there was a much lower proportion of non-discussed cases and the patients within that group were more often incompetent.

20 Cf. Otłowski, M., '*Voluntary euthanasia and the common law*', (2nd ed.), Oxford, University Press (2000), XIV.

Table 2. Proportions of non-discussed intentionally life-shortening non-treatment decisions

	no discussion	discussion unknown	discussion	incompetent patients in no-discussion group
Flanders 1998*	80.5%	0%	19.5%	74.4%
Hasselt 1997**	82%	0%	18%	89%
Netherlands 1990***	61.5%	0%	38.5%	94%

* Figures from Deliëns, L., Mortier, F., Bilsen, J., Cosyns, M., Stichele, R. vander, Vanoverloop, J., and Ingels, K., 'End-of-life decisions in medical practice in Flanders, Belgium: a nation-wide survey', (2000) 356, *Lancet*, 1806-1811.

** Figures from Deliëns, L. and Bilsen, J., *Handelwijzen van Hasseltse artsen rond het levenseinde van hun patiënten*, VUB/RUG (1998).

*** Figures from Maas, P. van der, Delden, J. van, and Pijnenborg, L., *Medische beslissingen rond het levenseinde. Het onderzoek voor de Commissie Onderzoek Medische Praktijk inzake Euthanasie*, 's-Gravenhage, Sdu Uitgeverij (1991) (no figures available for 1995).

A possible explanation for the observed differences is that in Belgium, the patient's autonomy is legally less clearly recognized and paternalistic medical practice appears to be more widely accepted.²¹ To curtail paternalistic practices and to secure the legal protection of the patient against infractions of the principle of informed consent, the federal Minister of Social Affairs, Public Health and the Environment is currently developing a legislative proposal on patient's rights.²²

Alleviation of pain and symptoms also intended to hasten the patient's death

This explanation is further confirmed by the data on medical decisions to alleviate pain and symptoms that are additionally intended to hasten the patient's death.

Again, in Flanders, high levels of non-discussion go with relatively low levels of incompetence of the patients in the non-discussion group. The paternalistic motivation for not discussing with the patient the alleviation of pain and symptoms that is also intended to end the patient's life, is explicitly indicated by the physicians in 29.3% of the cases ('No discussion was best for the patient; discussion would have done more harm than good').

²¹ See the contribution of Vezzoni, C., 'Engineering rights', in this Issue.

²² Avant-projet de loi relatif aux droits des patients. Ministère des Affaires Sociales, de la Santé publique et de l'Environnement.

Table 3. Proportions of non-discussed intentionally life-shortening decisions to alleviate pain and symptoms

	no discussion	incompetent patients in no-discussion group
Flanders 1998*	58 %	64 %
Hasselt 1997**	64 %	69 %
Netherlands 1990***	45 %	88 %

* Figures from Deliëns, L., Mortier, F., Bilsen, J., Cosyns, M., Stichele, R. vander, Vanoverloop, J., and Ingels, K., 'End-of-life decisions in medical practice in Flanders, Belgium: a nation-wide survey', (2000) 356, *The Lancet*, 1806-1811.

** Figures from Deliëns, L. and Bilsen, J., *Handelwijzen van Hasseltse artsen rond het levenseinde van hun patiënten*, VUB/RUG (1998).

*** Figures from Maas, P. van der, Delden, J. van, and Pijnenborg, L., *Medische beslissingen rond het levenseinde. Het onderzoek voor de Commissie Onderzoek Medische Praktijk inzake Euthanasie*, 's-Gravenhage, Sdu Uitgeverij (1991) (no figures available for 1995).

The general prevalence of a paternalistic approach toward end-of-life decision making is somewhat mitigated by the perception, as we showed elsewhere, that pain and alleviation decisions that also have a life-terminating intention are close to the use of lethal drugs. The estimations of the life-shortening effect of pain and symptom treatment also intended to end the patient's life are higher than for the same decisions without a life-shortening intention. Moreover, the decision making is more careful for the former than for the latter.²³ Generally however, the figures for non-treatment decisions and potentially life-shortening management of pain and symptoms confirm that the explanation of the high incidence of non-requested life ending in Flanders may not just lie in euthanasia being forbidden in Flanders.

4. Attitudes and Motivations of Physicians

From the previous paragraph, the conclusion can be drawn that in a non-negligible proportion of the cases, the patient's interest in being adequately informed and in participating in the end-of-life decision making is not sufficiently respected. We can turn now to the question of what physician characteristics and attitudes explain this deontological deficiency.

Before we present the empirical data on this matter, it should be noted that the application of ethical and legal standards to medical practice is largely a matter of individual conformity with the ethical and legal rules acquired during medical training periods. Much appears to depend on the physician's willingness to comply with the rules. It is true that compliance with the professional ethical standards, and even their elaboration, is, to some degree, ensured by the hospitals themselves. Some of them, for instance, have and enforce "do-not-

23 For details, see Bilsen, J., Deliëns, L., Mortier, F., Provoost, V., 'Intensiveren van pijn- en symptoombestrijding bij het levenseinde', (2001) 4, *Ethiek en Maatschappij*, 26-38.

resuscitate codes" (DNR). It is also true that the rather recently (1994) instituted ethics committees in the hospitals are increasingly taking up the role of forging of general rules, of testing their applicability to particular cases, and of controlling the rules.²⁴ Yet, there appear to be big differences between the hospitals in this respect. In some there are no DNR codes at all, and the ethics committees are young institutions that still have to prove their utility. Moreover, the family practitioners taking care of the patients dying at home have no general end-of-life guidelines at their disposal and are less subject to peer social control than their colleagues in hospitals.

The already mentioned survey of the Physicians newspaper *Artsenkrant* shows that roughly one third of the physicians refuses ex ante as well as ex post control of euthanasia.²⁵ In some specialities, for instance geriatrics, the rejection of control amounts to 47%. Two thirds of the physicians, however, are in favour of either an *a priori* authorisation procedure or *a posteriori* control or both. Up to 42% of the palliative care physicians prefers ex ante as well as ex post control of euthanasia. A major condition of success for any control mechanism, either ex post or ex ante, appears to be that physicians should be either the sole controllers (63% ex post; 48% ex ante) or that physicians should be well represented in a commission also encompassing a legal judge (30% ex post; 43% ex ante). In other words: professional peer control is preferred.

As already mentioned, under the euthanasia legislative proposal a national evaluation commission would be established, consisting of 8 physicians, 4 lawyers and 4 members representing organisations involved in care for terminally ill patients. The composition of the commission thus appears to be acceptable to the physicians willing to accept control. However, one third of the physicians, as a matter of principle, oppose the legal control of euthanasia. What do we know about these physicians? Some of the findings in the Flanders incidence study and in its pilot study for the city of Hasselt throw light on this question. Table 4 shows the relationship between, life-stance on the one hand, and on the other hand, the practice of euthanasia and non-requested life ending. The religiously affiliated physicians in Belgium are overwhelmingly Catholic, in a broad sense. Some of them strongly identify with the Catholic Church. Others are more reluctant to do so, but identify with the Catholic Faith. Therefore, the physicians could choose between two labels: 'Catholic' – the label most likely to be chosen by those identifying with the Catholic Church – and 'Christian', most likely to be chosen by Catholics critical of the church hierarchy. The category 'other' was constructed out of several denominations (Protestant, Reformed church, Anglican church, Muslim, Buddhist, and so on).

24 H. Nys, *Van ethiek naar recht? Het Raadgevend Comité voor Bio-Ethiek en de Medisch-Ethische Commissies in Ziekenhuizen*. Antwerpen/Apeldoorn, MAKLU, (1995).

25 Unfortunately, only very vague response rate data are offered. The total N = 823 respondents of which 611 were general practitioners and 211 were specialists.

Table 4. Incidence of voluntary and non-voluntary life-ending related to life-stance and university of graduation ****

Life-stance	Euthanasia + assisted suicide	Non-requested life termination
Christian	2.7 %	4.0 %
Catholic	1.7 %	1.7 %
Other	0.9 %	6.3 %
Not religious	1.4 %	9.4 %
P value χ^2 -test	0.457	0.0002
University of graduation		
Catholic	1.7 %	3.3 %
Other	2.5 %	7.0 %
P value χ^2 -test	0.352	0.03

* The percentages shown are percentages of numbers of cases studied in which end-of-life decision-making was possible for the physician. All sudden deaths were excluded

** Figures from Deliens, L., Mortier, F., Bilsen, J., Cosyns, M., Stichele, R. vander, Vanoverloop, J., and Ingels, K., 'End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey', (2000) 356, *The Lancet*, 1806-1811.

The table shows that as far as euthanasia is concerned, there are no significant differences between the members of the various groups. The incidences of unrequested life ending by lethal drugs, however, differ widely and are highly significant. The greatest contrast is between the not-religious (9.4%) and the Catholic group (1.7%). When calculated not on the number of cases in which an end-of-life decision was possible, but on all death cases, the incidence figure of unrequested life-termination for Catholic physicians is the same as that in the Netherlands (0.8%), i.e. four to five times below the figure for all physicians. For euthanasia (including assisted suicide) the figure for the Catholic physicians is 1.1%, i.e. equal to the general figure for all physicians.

The separate variables of university of graduation of the treating physician and life-stance indicate similar incidence figures in respect of euthanasia (including assisted suicide). Education in Belgium is still strongly pillarised. Pillarisation consists of the presence of several more or less strongly segregated clusters of social organisations, tied to religious and/or ideological cleavages within the population. Segregation is an expression as well as a contributory cause of a profound cleavage between, on one hand, the Catholic community, and, on the other hand, the non-believers.²⁶ University education is likewise segregated. It appears then, that the already observed life-stance differences associated with end-of-life practices are also at work at the level of university training.

Recently, several studies from a research group of sociologists based at the Free University of Brussels – the so-called TOR-group, i.e. *Tempus Revelat Omnia* – have pointed out that somehow, the values of society-wide solidarity and of responsibility for others are weaker within the categories of non-believ-

26 Huyse, L., *Passiviteit, pacificatie en verzuiling in de Belgische politiek na 1945*, Antwerpen, Standaard, (1970); Huyse, L., *De verzuiling voorbij*, Leuven, Kritak, (1987).

ers than in the religiously committed groups, and that these attitudinal differences translate into behaviour.²⁷ Is this also the case for physicians making decisions at the end of their patients' lives?

Few studies have associated physicians' attitudes with the incidences of their actual end-of-life decision making. In the Hasselt study this was done on the level of this one provincial city.²⁸ All physicians who had signed a death certificate received by mail both a questionnaire adapted from the questionnaire used in the Dutch incidence studies, and an attitudinal questionnaire, including nine five-point Likert-scale items in order to assess the attitudes of physicians toward euthanasia and assisted suicide (see table 5, first column). The items are selected to cover a wide range of issues connected with euthanasia: comprising patient self-determination (item 1), professional role of the physician (items 2 and 5), direct attitudes toward physician-assisted death on request (items 3 and 8), attitudes toward the regulation of euthanasia and assisted suicide (items 6 and 9), and attitudes toward palliative care as an alternative to physician-assisted death (item 7). A hierarchical cluster analysis of the answers to the attitude items was performed on the population of respondent physicians.²⁹ In addition, a life-stance variable was constructed on the basis of two further variables based on life-stance and affiliation and life-stance commitment. On the one hand, there was life stance affiliation ('what faith do you consider to be yours?') and on the other hand, commitment to one's life-stance when making end-of-life decisions in medical practice ('do you think that your faith is important when making professional end-of-life decisions?'). The affiliation variable distinguished between the Catholic physicians and the others, i.e. the non-denominationally religious and the non-believers (there were no representatives of other life stances).

'Commitment' was measured on a five-point scale (ranging from 'very important' to 'very unimportant' with a neutral point). On the basis of the cross-tabulation of the variables 'affiliation' and 'commitment' (each of them two-valued), it was decided that a new variable with three values was the most meaningful: committed Catholics (CC), committed non-Catholics (CNC) and non-committed physicians (NC). The cluster analysis revealed the presence of three readily interpretable clusters of physicians (see table 5).

There is a majority cluster of physicians (N = 58) in favour of, at least in some circumstances, and asking for more regulatory clarity, certainly in the form of professional guidelines, and to a lesser extent in the form of special legislation.

27 See Van Ootegem, L. (ed.), *De markt van de vrijgevigheid: giften in Vlaanderen doorgelicht*, Leuven, Acco, (1993); Elchardus, M. *et.al.*, 'Hoe negatief kan vrijheid zijn? Ongeloof, vrijzinnigheid en populatistische ontvoogding', in: *Kiezen is verliezen*, Swyngedouw, M. *et.al.* (eds.), Leuven, Acco, (1993), 27-39.

28 The primary research population consisted of all deaths in the year 1996 (N= 970).

29 For more details, see Mortier, F., Deliens, L., Vander Stichele, R., Bilsen, J. and Bernheim J., 'Euthanasia and other end-of-life decisions in Hasselt, Belgium: attitudes of physicians and correlations with their practices', (submitted).

A smaller cluster ($N = 21$) is also in favour of euthanasia. Yet, respect for the autonomy of the patient does not appear to be their main consideration in accepting the practice. The lack of general endorsement by these rule-adverse physicians of the right to decide for oneself about one's life and death (only 14%) is matched by their rejection (only 5%) of the impact of legislation on the incidence of euthanasia. This group appears to be rather paternalistic on the ethical plane, and rather corporatistic on the societal level. The smallest cluster ($N = 13$) is clearly opposed to euthanasia, believes that the legal prohibition of euthanasia and assisted suicide is warranted, and is in favour of clear professional guidelines – presumably prohibitive – regarding these issues. An apparent incongruity is the strong endorsement by this group of the autonomy principle relative to life and death. Yet, this may be explained by their equally strong endorsement of the view that canvassing euthanasia and assisted suicide as an option is not the task of the physician. Our respondents may have thought that respect for the autonomy of the patient is compatible with the idea that providing the patient with the means to exercise that autonomy falls outside the scope of the physician's professional role. Table 6 shows how some attitudinal and socio-demographic variables of the physicians correlate with end-of-life decision making. The cluster groups are clearly differentiated by the distribution of the types of end-of-life decisions they tend to make. The group opposed to euthanasia, for instance, had not a single case of active life ending, while non-treatment decisions were proportionally rarely opted for by the rule adverse physicians in favour of euthanasia. The latter group had the highest rate of active life ending. Moreover, there are marked differences as far as respect for the patient's autonomy is concerned. The last column (representing the situation where no discussion has taken place) lists a rough indicator of the carefulness of end-of-life decision making: the end-of-life decisions were subdivided into the cases where the physician had never discussed the decision with the patient, although the patient was competent, and the other cases.

The patient was classified as incompetent when the physician gave at least one of the following reasons for not consulting the patient: young age, temporarily or permanently lost or impaired consciousness, dementia or a psychiatric disease. The patient was considered competent when there had been a discussion or when the physician gave at least one of the following reasons for not consulting the patient: emotional vulnerability, the patient's best interest, or discussion having been more harmful than beneficent.

The rule adverse physicians also in favour of 'active' life ending made a majority of decisions without even consulting the competent patient. These practices support the interpretation that the rule adverse cluster is essentially a paternalistic group. To get the profile of this group right, it should be noted that the overall frequency of end-of-life decision making is significantly lower in this group than in the others. This probably means that the physicians in this group are more inclined to treat till the end. The group in favour of both regulation and euthanasia had also been involved in non-discussed cases of end-of-life decision making on behalf of competent patients, but to a much lesser ex-

tent. Moreover, members of this group were less inclined to use 'active' methods. The group opposed to euthanasia, interestingly, registers no non-discussed cases at all and is adverse to 'active' life ending.

The presence of the rule adverse group, then, clearly poses a problem for achieving legal control. In our opinion, legalising euthanasia and introducing an obligation to report to a National Commission is unlikely to change the behaviour of these physicians. They are attitudinally against regulation and are likely to perceive reporting as an embarrassing cost. They did not comply with the prohibition of active life-ending, so why would they comply with the obligation to report practices that, given their medical practice, will largely remain illegal? No doubt they will understand that one National Evaluation Commission of 16 members cannot control an estimated total of 2,500 cases of active life ending per year. Our guess is also that the proportion of cases of alleviation of pain and symptoms with the co-intention to end the patient's life will rise for these physicians.

The data on the life-stance groups are equally interesting. The decision making in the committed Catholic and the committed non-Catholic group (non-believers, probably humanists) is differently distributed over the types of end-of-life decisions. As one would expect, the Catholics are more drawn toward the alleviation of pain and symptoms. Intentional life ending is rare with them. The committed non-Catholic group, on the other hand, does not appear to make a distinction between 'killing' and 'letting die'. Intentional and active life-ending represent comparatively large parts of their decision making. However, the two groups are similar as to the carefulness of their decision making: the no-discussion group is small to non-existent in the two cases. The non-committed group, on the other hand, comprising Catholics as well as non-believers, has a relatively high rate of non-discussed life ending in competent patients. Non-treatment decisions are their favoured type of decision at the end of life.

Bearing in mind that the non-committed group consists of physicians who stated that their life-stance is not important in their professional practice, it may be conjectured that conversely, firm beliefs at the level of life-stance are associated with careful medical practice at the end of life. Moreover, the fact that these committed groups are guided by self-imposed rules also appears from their preferred end-of-life decisions. Prohibitions of 'killing' translate into low active life-ending rates (for the Catholics) and the norm of respect for the autonomy of the patients translates into discussing where possible, i.e. with competent patients (for the humanists). This conclusion partly contradicts the findings of the Brussels' research group, mentioned above, but is well in line with its basic hypothesis: having effective collective behavioural norms is likely to be associated with careful medical practice. However, life stance commitment is not to be confused with religious affiliation, since religious people as well as non-believers may share effective behavioural norms with other members of their group.

The procedure for reporting and evaluating euthanasia will probably be supported by the committed groups, who already show a concern for carefulness. Although no firm quantitative conclusions are warranted from the Hasselt study, we may safely hypothesise that the committed groups in Flanders are in a minority. Much depends then on the reactions of the non-committed group. Since the non-committed physicians are more likely than the committed to belong to the group in favour of euthanasia, but asking for clear rules, there is at least some hope.

5. Conclusion

The medical profession in Belgium and more particularly in Flanders, essentially consists of several heterogeneous groups, that are likely to respond differently to the legalisation of euthanasia and to the imposition of the associated notification procedure. Generally speaking, there is little organised professional support for the new legislative proposal, although a large number of individual physicians are in favour of the new law as well as of legal control. Legal reform, although necessary, will probably be insufficient to achieve effective control of active life ending not to mention the other, 'normal', end-of-life decisions. The main question is how to assure that less careful physicians – and, as we argued, they share a recognisable professional profile – will come to share elementary norms. In our opinion, internal professional control relying on the ethic committees in the hospitals, medical education, and the elaboration and enforcement of medical protocols may present opportunities which can enhance norm compliance. If these measures do not accompany the new law, effective legal control will remain low, although no doubt higher than at present.

CONCLUDING REMARKS

Comparative Reflections: Is the Dutch Case Unique?

John Griffiths

1. The Question

The relevance for other societies of the Dutch experience with regulated euthanasia is frequently dismissed almost off-handily with the observation that, while regulation may work satisfactorily in the Netherlands, this is due to peculiarities of the Dutch situation. Even the Dutch insistence that their approach to euthanasia is not an 'export product' sometimes seems not so much a matter of modesty as of an almost smug assumption of local particularity. It may prove interesting, by way of reflection on the various essays in this Issue, to consider a bit more systematically than is usually the case the question, what if anything is unique to the Dutch case, and whether it matters.¹

Let us first specify the question. In the Netherlands a rather lengthy process, described by Weyers (in this Issue), led to the legalisation of euthanasia (together with physician-assisted suicide) subject to certain substantive and procedural conditions. The result of this is a regulated medical practice that, while there is general agreement on the need for improvement (especially as far as reporting is concerned), is socially uncontroversial and unproblematic. Belgium is about to enact a law legalising euthanasia in a similar way (see Adams in this Issue) and there are indications that France, for example, may follow suit.² In the United States, physician assistance with suicide has been legalised in Oregon, and it seems only a matter of time before referenda similar to that in Oregon succeed elsewhere. The question I want ultimately to raise is whether the medical practice of legalised euthanasia will prove equally uncontroversial and unproblematic in other countries..

We must put one complication aside, and that is the fact that, despite what is often supposed, the Netherlands is not the first or the only country in which euthanasia, in the form of assisted suicide, is legal. Continental criminal codes historically did not regard suicide as a crime and assisting another to commit it was therefore also not criminal (unless, as in the Netherlands, specifically prohibited). The situation is complicated in countries like Germany and France

1 In these short reflections, I deal only with the question to what extent any form of Dutch uniqueness is relevant for the project of *regulating* euthanasia. Something else that is characteristically and, so far, almost uniquely Dutch is empirical research concerning the practice of euthanasia and its regulation. As the contribution of Van der Heide et al. in this Issue makes clear, whatever may be the case with regulation, Dutch expertise in *researching* euthanasia definitely is exportable.

2 See *Newsletter MBPSL*, nr. 4, July 2000, 'Special activities' (www.rechten.rug.nl/mbpsl).

because of the existence of a duty to rescue a person in danger of death, that apparently is considered applicable to the situation of physician-assisted suicide. But in Switzerland, there is a well-established, institutionalised practice of assistance with suicide (in which doctors, however, play only a limited role); the practice is apparently uncontroversial and unproblematic. To the extent there may be relevant differences between euthanasia and assisted suicide, we must therefore restrict the discussion to euthanasia if we are to have anything left to explain in terms of possibly unique features of Dutch society.

2. What Is *Definitely Not Unique* to the Dutch Situation?

There is a great deal about the Dutch situation that seems intuitively relevant to the social acceptability of a medical practice of regulated euthanasia and that is often mentioned in that connection:

- 1 modern medicine's ability 'artificially' to postpone death long beyond the point at which there is any chance of recovery;
- 2 increasingly frequent requests by dying patients and those close to them that their doctor help them to put an end in a humane and dignified way to such a situation of medically-postponed death;
- 3 increasing cultural acceptance of the idea of the autonomy of the patient, reflecting itself both in law (e.g. the doctrine of informed consent; recognition of advance directives) and in medical practice (e.g. the practice of informing a patient of his terminal condition);
- 4 a modern health-care system in which medical care at the end of life does not impose severe financial burdens on patients and their families;
- 5 strong support in public opinion for legalisation of euthanasia;
- 6 strong support among doctors for legalisation of euthanasia;
- 7 a widespread medical practice both of euthanasia (except in the Netherlands, largely covert) and of related ways of shortening the patient's life, such as abstention and pain relief;
- 8 the presence of 'moral entrepreneurs': key individuals promoting legal change.

However, none of this is unique to the Netherlands, and most of it applies more or less equally to all Western countries (although the fourth factor obviously does not obtain in the United States). In this Issue, Mortier and Deliens and Otłowski show how widespread the practice of euthanasia and related practices are, and Vezzoni how generally accepted the idea of patient autonomy and the related practice of advance directives has become. The opinion research of Trappenburg and Van Holsteyn is far more sophisticated than is to be found elsewhere, but the fact that a (large) majority of the population supports legalisation of euthanasia has been established in many countries. Similarly, research

in many countries has shown support among doctors (although not their professional organisations) for legalisation.

3. What Is *Arguably Special* about the Netherlands?

The reasons usually given to explain the fact that, despite similarities in the conditions mentioned above, the Netherlands is so far the only country to have legalised euthanasia, usually invoke supposedly typical features of Dutch political culture:

- 9 an emphasis on toleration, compromise, practical solutions to morally controversial issues (abortion, sex, drugs), and a general distrust of absolute, ideological positions on public issues (Weyers in this Issue³) – all this being very unlike, for example, American political culture (Battin in this Issue);
- 10 a commitment to social equality and ‘democracy’ (which in Dutch parlance is more than a governmental form and includes broadly the right to have a say in decisions affecting one’s life, work, living situation, etc.), to social solidarity (reflected in a comprehensive welfare state), and to individualism (not so much in the American sense of ‘every man for himself’ but rather in the sense that everyone is personally responsible for making choices about his life, which ought in principle to be respected by others⁴);
- 11 ideologically ‘open’ politics, given to inclusive rather than exclusive ways of dealing with radical and potentially threatening ideas or groups, and a political elite inclined not to resist social change but to incorporate it within the existing social and legal structures;⁵
- 12 a stable multi-party system in which a modest number of nationally-significant political parties are, as a result of electoral proportional representation, more or less permanently represented in parliament, none of them with an absolute majority; pressure groups or ideologies can usually ‘capture’ at most one of these parties; political decision-making is necessarily a matter of compromise (this condition is absent in two-party systems lacking proportional representation, such as the US and the UK; it is weak in countries such as France and Germany);
- 13 a tradition of decentralised decision-making authority and of looking to self-governing groups (such as professional associations) as sources of social control over the activities of their members (a condition allegedly absent in France, for example).

3 See also Weyers, H., ‘Prologue: the Netherlands and the Dutch,’ in *Euthanasia and Law in the Netherlands*, Griffiths, J., Bood, A., and Weyers, H., Amsterdam, Amsterdam University Press (1998), 9-13.

4 *Ibid.*

5 *Ibid.*

The trouble with such cultural characteristics as indicia of Dutch ‘uniqueness’ is that, while they do describe the Dutch situation reasonably well, they also apply to a greater or lesser extent to many other countries (a few apparent exceptions have been noted above). Attribution of one or another of them to any given national culture as a way of ‘explaining’ some peculiarity of legal development (such as the Dutch legalisation of euthanasia) is unavoidably impressionistic and disputable.

Nevertheless, while it would be arbitrary to ascribe any such cultural characteristic uniquely to a particular country, some specific local combination presumably does account for the different courses legal development has taken. But specifying the particular combination characteristic of the Netherlands seems a doomed enterprise. Nor can we draw any conclusions concerning the likely effects of a legalised euthanasia practice in another country from such an unspecifiable supposition.

4. What Does Seem *Definitely Unique* about the Netherlands (to date)?

I conclude that there is only one seemingly relevant factor which one can usefully identify as specifically characteristic of the Netherlands:

- 14 a medical profession whose leadership took the lead in promoting legalisation of euthanasia and accepted primary responsibility for working out the substantive and procedural conditions under which euthanasia is acceptable (contrast Belgium, for example, where, as Adams describes in this Issue, the representatives of the medical profession have opposed legalisation).

The particular way in which the Dutch medical profession has reacted to a fairly common legal, medical-technological and cultural situation affords a possibly ‘unique’ – if probably only partial – explanation of the legalisation of euthanasia in the Netherlands. The profession’s role in the development of Dutch euthanasia law has been described by Weyers (in this Issue).⁶ What I want to do in bringing these short reflections to a close is to return to the ultimate question I raised at the beginning: what are the implications of proposition 14 for the future of legalised euthanasia in the Netherlands and elsewhere?

6 See also Griffiths, J., ‘Self-regulation by the medical profession of medical behavior that potentially shortens life,’ in *Regulating Morality. A Comparison of the Role of the State in Mastering the Mores in the Netherlands and the United States*, Krabbendam, H. and Napel, H.-M. ten (eds), Antwerp/Amersfoort, Maklu (2000), 173-190.

5. What Can We Predict about the Social Consequences of Legalised Euthanasia?

The ‘dangers’ – let us use a more neutral term, the social consequences – of legalising euthanasia are commonly expressed in terms of a ‘slippery slope’ (see Schwitters in this Issue). In the most general terms this notion comes down to the innocuous proposition that from one thing will come another. Depending on one’s moral preferences, one can regard the hypothesised consequences as desirable or undesirable: one can ‘slip’, in other words, into moral grace as well as into depravity.

Let us put two things that can be referred to with the expression of a ‘slippery slope’ to one side. The first is the so-called conceptual thesis, according to which allowing one thing, which is *not* in itself morally objectionable, will commit one to allow another thing that *is* morally objectionable.⁷ There is nothing to be said for the conceptual thesis since no ‘logic’ can prohibit us from making relevant moral distinctions. Only the ‘empirical’ version of the slippery-slope argument is interesting.

The second idea I want to put to one side is, by contrast, interesting, undoubtedly sometimes true, but for reasons of democratic principle unacceptable as an argument against legal change. This is the thesis that a given legal change – in itself not objectionable – will in time, as it becomes accepted and familiar, affect the moral assessment of other things that most people now consider objectionable, and thus lead to moral change in an undesired direction. Legalising euthanasia may lead to a general moral reassessment of, for example, the importance of autonomy, and hence to acceptance of euthanasia in the absence of any ‘medical’ reason, or it may lead to a reassessment of the value of human life and hence to acceptance of ‘non-voluntary’ euthanasia. There is nothing ‘logically’ necessary about any of this, of course (I have rejected the conceptual version of the slippery slope above), but empirically such processes of moral change seem quite plausible. Nevertheless, the prediction of undesired moral change on related subjects as a consequence of legal change that is in itself desirable, is unacceptable as an argument against such legal change. This is because it amounts to an attempt by the current generation to bind the moral judgement of future generations, by manipulating the situation in which they make their moral judgements. It is morally – and constitutionally – wrong to try to determine for future generations how they should think about some moral question.

What is left, then, of the slippery slope notion is not possible to confine within the limits of what is legalised. To make the discussion concrete, let us

⁷ The slippery-slope argument presumably also applies to prohibitions: forbidding something, that ought to be forbidden, leading to the prohibition of things that are unobjectionable or even good. An argument of the type: the cure will prove worse than the disease. I cannot recall having seen the argument made in that direction, although it does seem potentially applicable to the case of prohibition of euthanasia (supposing euthanasia in itself to be worthy of prohibition).

use the example of the common argument that legalising euthanasia will make it impossible to prevent termination of life without a request. This contention requires more critical appraisal than it usually gets.

In the first place, the contention assumes that in the absence of legalisation such termination of life will not occur, or at least not as frequently: the slippery slope, in other words, is from effective to ineffective control. Such an effect of a legal change is surely possible (imagine the effects on control of changing maximum speed limits into a general requirement of a 'safe speed'). But there is no evidence that any such thing has taken place in the Netherlands as a result of the legalisation of euthanasia: no evidence that termination of life without a request has become more frequent since legalisation in 1984, and no evidence that it is more frequent in the Netherlands than elsewhere. In fact, such evidence as there is points in the other direction (see Mortier and Deliens; and Otłowski, in this Issue). More generally, it seems pretty clear that many of the things to which opponents of legalising euthanasia point as the horrors to which legalisation will lead, in fact pre-existed legalisation of euthanasia in the Netherlands and are at least equally frequent in countries where it remains illegal, and if anything are under better control in the Netherlands than elsewhere. In short, there is no *post hoc* here.

In the second place, the contention assumes that the *reason* for the increase in the frequency of termination of life without a request – if it had taken place – would lie in the legalisation of euthanasia and not – for example – in the fact that such behaviour had come to be regarded as not always and under all circumstances objectionable.⁸ Absent convincing evidence on the point, the contention is missing its *propter hoc* as well.

In short, there seems no reason to suppose that the predicted horrors have materialised as a result of legalisation of euthanasia. Why not? Two reasons suggest themselves: the slope may not be so slippery after all (it may be possible to draw lines and to enforce them), or we may have been more or less at the bottom of it anyway with nowhere to go but up. Let me deal with the second possibility first.

Those who urge upon us the dangers of a legalised practice of euthanasia tend to concentrate on 'euthanasia' in isolation and to ignore the much larger context of physician-negotiated death of which euthanasia – legal or illegal – is but a small part. In countries with advanced health-care systems, the timing or the precise manner of roughly half of all deaths is determined by something the doctor does or does not do. Of these 'physician-negotiated deaths' roughly 9 out of 10 are either due to abstention (refraining from or not initiating further life-prolonging treatment) or to pain-relief in amounts likely to accelerate

8 For reasons discussed above, such a supposed effect (often labelled 'symbolic', and the last desperate refuge of defenders of apparently ineffective legal measures) cannot in itself be a legitimate reason for maintaining a criminal prohibition.

death.⁹ Only a small number of all deaths (in the Netherlands, 3.4%; in Belgium 4.4%), are due to euthanasia, assistance with suicide, and termination of life without an explicit request (see Mortier and Deliens, in this Issue).

The importance of these facts for the effectiveness of control lies in the 'constructibility' of the various categories of physician-negotiated death. To a considerable extent, a doctor can choose how to bring about a shortening of his patient's life and how to describe what it is that he has done. If one of the possibilities is unattractive for any reason, for example because it is illegal, he can accomplish the same result in a different way or under a different name. To the extent the horrors predicted should euthanasia be legalised were already taking place before legalisation but were characterised by the responsible doctor as deaths due to abstention or pain relief, it is not surprising that legalisation has not lead to a slippery slope. All that has happened is that what was taking place already has to some extent come out into the open as 'euthanasia', where it can be subject to some control. For precisely the same reason, no downward slippery slope is to be expected in other countries with similar levels of physician-negotiated death; they, too, have nowhere to go but up.

The second reason no slippery slope seems to have materialised is that it has proven possible to control the practice of euthanasia. To some extent this may be simply a consequence of the openness that legalisation makes possible, a practice that takes place in full view being less dangerous than one that takes place in secret. To the extent this is the case, the horrors feared from legalisation will in fact decrease, in any country where a significant proportion of physician-negotiated death is currently crypto-euthanasia. But one could go further than mere openness and seek to subject the practice of euthanasia to specific substantive and procedural controls. This is the route that the Netherlands has followed and as Klijn shows (in this Issue), it seems to have had some success. It is at this point that I think we can seriously raise the question, whether this success can be repeated elsewhere.

6. The Importance of Self-Regulation

The success of Dutch regulation of euthanasia has been intimately bound up with the very active role of the organised medical profession in the process of legalisation and in particular the formulation and propagation of the 'rules of careful practice' with which Dutch doctors are required to comply. The phe-

9 The veracity and accuracy of self-reports by doctors of the frequency of death due to pain relief can be regarded sceptically. See Admiraal, P. and Griffiths, J., 'Sterven aan pijnbestrijding,' (2001)12, *Medisch Contact*, 463-466; Thoms, A., and Sykes, N., 'Opioid use in last week of life and implications for end-of-life decision-making,' (2000) 356, *The Lancet*, 398-399. This does not significantly affect the argument here; in fact, to the extent deaths allegedly due to 'pain relief' are in fact due to doses of drugs so high as to have no plausible relationship to treatment of pain and other symptoms, such scepticism gives the argument an important source of support.

nomenon of self-regulation by the Dutch medical profession has not been limited to euthanasia. In a recent article I describe similar processes, some of them ongoing, of self-regulation of other forms of medical behaviour that potentially shortens life (mbpsl): in the cases of non-conscious patients (new-born babies and persons in coma), psychiatric patients, and termination or non-initiation of life-prolonging treatment:¹⁰

The norms and procedures applicable to MBPSL have (with the exception of the requirement of reporting) largely emerged from within the medical profession itself. (...) For each new issue, the same pattern of legal change has repeated itself: first the profession itself has worked out a solution, then the prosecutors and the courts have adopted the professional solution in deciding cases and finally the legislature has accepted the results reached elsewhere (although so far [except very recently for euthanasia] this acceptance has not led to actual legislation). In the case of euthanasia, the process [...] involved rather complex interaction with the courts, the prosecutorial authorities, and even the legislature (whose successive proposed bills influenced legal development). In the case of other MBPSL, the medical profession has acted more autonomously and the process has been more straightforwardly one of self-regulation.

There is good reason to suppose that the widespread support that the rules enjoy among Dutch doctors, and the increasing degree to which they follow them in practice,¹¹ results in important part from the fact that the rules themselves are largely the product of professional self-regulation. From the same article:¹²

On theoretical grounds one would have a number of reasons for predicting that legal regulation that emerges from a process of self-regulation would be more effective than regulation imposed from outside the social group concerned:¹³

1. The requirements are more likely to be known to the actors on the shop floor when they, or their own professional association, have been instrumental in working them out. They are also more likely to interpret the requirements in the appropriate way.
2. The requirements are more likely to be (seen to be) adapted to the practical situation confronted by actors on the shop floor. There will be less professional resistance to what is required.

10 See Griffiths, J., 'Self-regulation by the Dutch medical profession of medical behavior that potentially shortens life,' above, 183.

11 See Griffiths, J., Bood, A., and Weyers, H., *Euthanasia and Law in the Netherlands*, above, 216-222, for data on knowledge, support and actual practice with regard to the rules of careful practice.

12 *Ibid.*, 187-188.

13 See Griffiths, J., *The Social Working of Legal Rules* (forthcoming).

3. The requirements will be more likely to enjoy the support of informal social control from within the professional group itself than requirements imposed from outside. Since – as is often the case with legal regulation, but probably particularly so in this case – formal legal agencies are not likely to be in a position to exercise much effective control over the situation on the medical shop floor, the support of informal professional control is probably critical to legal effectiveness.

The upshot of this argument is that if, as appears to be the case, the active role of the Dutch medical profession in the regulation of legalised euthanasia is and continues to be unique, the successes of Dutch regulatory policy, modest as they are, will be harder to replicate elsewhere – in Belgium, for example. In the absence of support from well-organised professional associations with high legitimacy among doctors, we should expect it to take longer in such countries before externally-imposed rules of careful practice are known to, accepted by and in practice followed by doctors.¹⁴ This does not mean that there will be a downward slippery slope – we have seen above that there may well be nowhere to go but up – but that the upward slope may well be less steep than it has been in the Netherlands.

14 Oregon may prove be an interesting test case for such a prediction, although the minuscule numbers involved and the extremely restricted character of the legalization may stand in the way of convincing results. Furthermore, although the Medical Association was at first opposed to legalization, it later took a neutral position and the rules enacted emerged from a process in which local doctors were well represented which lends to the Oregon case some element of self-regulation. See Hillyard, D., and Dombrink, J., *Dying Right. The Death with Dignity Movement*, London -New York, Routledge and Kegan Paul (2001) ch.3.

ABOUT THE AUTHORS

About the Authors

Maurice Adams (*University of Antwerpen, Belgium*)

Studied law at the Universities of Maastricht (the Netherlands, 1988) and Leuven (Belgium, 1990), and philosophy of law at Oxford University (United Kingdom, 1991). PhD in Law at the University of Leuven (1997). Currently he is professor of law at the Faculty of Law of the University of Antwerp (UFSIA), where he teaches jurisprudence and comparative law. The last few years he has published widely on the relation between law and ethics, especially focusing on the regulation of euthanasia. He advised the Committee of the Belgian Senate which took the lead in discussing Belgian legislation on euthanasia.

(maurice.adams@ua.ac.be)

Margaret P. Battin (*University of Utah, USA*)

Distinguished Professor of Philosophy and Adjunct Professor of Internal Medicine, Division of Medical Ethics, at the University of Utah. She has authored, edited, or co-edited twelve books, among them a text on professional ethics; *Ethics in the Sanctuary*, a study of ethical issues in organized religion; *The Least Worst Death*, a collection of essays on end-of-life issues written over the last fifteen years; *Ethical Issues in Suicide*, trade-titled *The Death Debate*. She has also been engaged in research on active euthanasia and assisted suicide in the Netherlands, and has held the Spinoza Chair at the University of Amsterdam Medical School. She is currently at work on a historical sourcebook on ethical issues in suicide. In 2000, she was a co-recipient of the Rozenblatt Prize, the University of Utah's most prestigious award.

(mp.battin@m.cc.utah.edu)

Luc Deliens (*Free University Brussels, Belgium*)

PhD in Health Sciences (1998). Professor of health sciences, Department of Medical Sociology, Free University of Brussels; and senior-researcher at the Department of Social Medicine, Institute for Research in Extramural Medicine, VU University Medical Center, Amsterdam. In 2000 he was the co-ordinator of the research team that carried out a nation wide study on end-of-life decision making in Flanders, Belgium. Currently, he is leading several research projects on end-of-life decision making in Brussels, Belgium; and on palliative care in Amsterdam, the Netherlands

(luc.deliens@vub.ac.be)

John Griffiths (*University of Groningen, the Netherlands*)

Professor of sociology of law, Department of Legal Theory, Faculty of Law, University of Groningen. In recent years his theoretical attention has been primarily addressed to the social working of legal rules. His empirical research has applied this approach in particular to problems of the regulation of medical behaviour concerning the end of life. In 1998 he, A. Bood and H. Weyers published *Euthanasia and Law in the Netherlands* (Amsterdam University Press). Currently he is directing a interdisciplinary, comparative research program on the *Regulation of medical behaviour that potentially shortens life (MBPSL)*. (j.griffiths@rechten.rug.nl)

Agnes van der Heide (*Erasmus University Rotterdam, the Netherlands*)

MD, PhD (1994), is senior-researcher at the Department of Public Health of the Erasmus University Rotterdam. In 1995 she was a member of the research team that carried out a nationwide study on end-of-life decision making. Within this study, she co-ordinated a substudy on end-of-life decision-making in neonatology. Currently, she is leading several research projects on end-of-life decision-making and terminal care. (vanderheide@mgz.fgg.eur.nl)

Joop van Holsteyn (*Leiden University, the Netherlands*)

PhD in political science (1994) Leiden University. Assistant professor at the Department of Political Science, Leyden University. His research interests include elections and electoral behavior, opinion polls and right-wing extremism. He has published in *Acta Politica*, *West European Politics*, *Politics* and *Public Opinion Quarterly*. Together with Margo Trappenburg he wrote (in Dutch) *Het Laatste Oordeel. Meningen over nieuwe vormen van euthanasie* (The final judgment. Opinions on new forms of euthanasia, Ambo, Baarn, 1996) and an article in English on euthanasia in the Netherlands, in *Patient Education and Counseling* (35/1, 1998). (Holsteyn@fsw.LeidenUniv.nl)

Albert Klijn (*Ministry of Justice, the Netherlands*)

PhD Sociology of Law (1991), University of Utrecht. Senior Researcher at the *Research & Documentation Center* of the Ministry of Justice (WODC). He has a long-standing research interest in the legal profession, legal aid, civil litigation and dispute resolution. He is a member of the International Working group for the comparative study of the Legal Professions. As Associate Professor he participates to the research program *Regulation of medical behavior that potentially shortens life (MBPSL)* at the Department of Legal Theory, Faculty of Law, University of Groningen. His research focuses on the issue of legal control of medical behaviour. Currently he is managing editor of *Recht der Werkelijkheid*, the Journal of the Flemish/Dutch Association for Socio-legal Studies. (aklijn@wodc.minjust.nl)

Paul J. van der Maas (*Erasmus University Rotterdam, the Netherlands*)

MD, PhD (1979). Was head of the Department of Public Health of the Erasmus University Rotterdam until April 2001. His main interests concerned the estimation of the effects of risk factor modification and medical interventions on overall population health status and the costs of health care, the development of an optimal programme for breast cancer screening and the development of a non-disease specific quality-of-life indicator (Euroqol). In 1990, he directed the 'Rommelink study', which was the first nationwide empirical study on end-of-life decision making. In 1995, he was responsible for a similar study, together with Gerrit van der Wal. Currently, he is dean of the Faculty of Medical Science of the Erasmus University Rotterdam.
(vandermaas@facb.ffg.eur.nl)

Freddy Mortier (*University of Ghent, Belgium*)

PhD Philosophy (1986), Ghent University. Professor of Ethics at the Ghent University. He is director of the Centre for Environmental Philosophy and Bioethics at the same university and a member of the Federal Advisory Board on Bioethics. He is a member of the research program on End-of-life Decisions in Medical Practice in Belgium, based at the Free University of Brussels and the Ghent University, and is promoter or co-promoter of several projects within that program. He was a member of the research group that conducted the first nationwide epidemiological study on end-of-life decision making in Belgium.
(Freddy.Mortier@rug.ac.be)

Bregje Onwuteaka-Philipsen (*Free University Amsterdam, the Netherlands*)

MA, PhD (1999), is a health scientist who participated in the 1995 nation-wide study on end-of-life decision-making in medicine, in which she co-ordinated a sub-study on reported cases of physician-assisted death. Currently she is project leader of several projects, among them a study on forgoing artificial administration of fluids and food in psychogeriatric nursing home patients and an evaluation study of the project 'Support and Consultation for Euthanasia in the Netherlands'.
(b.philipsen.emgo@med.vu.nl)

Margaret Otłowski (*University of Tasmania, Australia*)

PhD in Law (1993). Associate Professor in the Faculty of Law at the University of Tasmania, Australia. Her research has principally been in the area of medical law, including considerable attention to end of life issues. Her doctoral thesis was on the subject of euthanasia and she has since published on this topic, her main contribution being a book published with Oxford University Press, *Voluntary Euthanasia and the Common Law* (1997). She is a member of the International Advisory Committee of the research program 'Regulation of medical behaviour that potentially shortens life' (MBPSL) being carried out at the Department of Legal Theory, Faculty of Law, University of Groningen.
(margaret.otłowski@utas.edu.au)

Rob Schwitters (*University of Groningen, the Netherlands*)

PhD Sociology of Law (1991), University of Utrecht. He participates as Assistant Professor in the '*Regulation of medical behavior that potentially shortens life*' (MBPSL) at the Department of Legal Theory, Faculty of Law, University of Groningen. He is also Scandinavian correspondent for the *Research & Documentation Center* of the Ministry of Justice (WODC), the Netherlands, and affiliated with the Institute for Sociology of Law of the University of Oslo. His research focuses on juridification processes and transformations of legal rationality.

(r.j.s.schwitters@rechten.rug.nl)

Margo Trappenburg (*Utrecht University, the Netherlands*)

PhD in political science (1993) Leiden University. Associate Professor at the Utrecht School of Governance, Utrecht University. Her research interests include ethical issues such as the distribution of health care, immigration policy, and multiculturalism. She published (in English) in the *Journal of Political Philosophy*, the *Cambridge Quarterly of Health Care Ethics* and *Acta Politica*. Together with Joop van Holsteyn she wrote (in Dutch) *Het Laatste Oordeel. Meningen over nieuwe vormen van euthanasie*. (The final judgment. Opinions on new forms of euthanasia, Ambo, Baarn, 1996) and an article in English on euthanasia in the Netherlands in *Patient Education and Counseling* (35/1, 1998).

(m.trappenburg@usg.uu.nl)

Cristiano Vezzoni (*University of Groningen, the Netherlands*)

MA Sociology (1998) University of Trento, Italy. He is currently a Ph.D. candidate at the Department of Legal Theory, Faculty of Law, University of Groningen, working as a member of the research program *Regulation of medical behaviour that potentially shortens life* (MBPSL). His research project deals with the health-care decision-making process in the case of incompetent patients, focusing on the use of advance directives

(c.vezzoni@rechten.rug.nl)

Gerrit van der Wal (*Free University Amsterdam, the Netherlands*)

MD, PhD (1992), is professor in Social Medicine, head of the Department of Social Medicine and vice-director of the Institute for Research in Extramural Medicine of the Free University Amsterdam. He has many years' experience in working both as a general practitioner and as an inspector for health care. In the early 1990s, he was involved in two studies on euthanasia and physician-assisted suicide, one concerning general practitioners and one concerning nursing home physicians. In 1995, he was, together with Paul van der Maas, responsible for the second nation-wide study on end-of-life decision-making. Currently, he is supervisor of several studies on quality of care, prevention, end-of-life decisions and palliative care.

(g.van_der_wal.emgo@med.vu.nl)

Heleen Weyers (*University of Groningen, the Netherlands*)

MA philosophy (1995); MA history (1995) University of Groningen. Presently she teaches sociology of law at the Department of Legal Theory of the University of Groningen. With John Griffiths and Alex Bood she co-authored *Euthanasia and Law in the Netherlands* (Amsterdam University Press, 1998). She is preparing a dissertation on the process of legal change with respect to euthanasia. She also participates the research program *Regulation of medical behaviour that potentially shortens life* (MBPSL).
(h.a.m.weyers@rechten.rug.nl)

In July 2001, the Human Rights Committee, established to safeguard the rights laid down in the International Covenant on Civil and Political Rights, addressed itself to the human rights situation in the Kingdom of the Netherlands. Among other concerns, the Committee raised some questions about the situation regarding euthanasia and assisted suicide. Moreover, the Committee expressed doubts about the control system.

In a way, one might read this special issue of *Recht der Werkelijkheid* as a preliminary study for the next report of the Dutch government to the Human Rights Committee. Significantly, however, quite independently of this recent call from the Human Rights Committee for further explanation of the Dutch position on euthanasia, there has been ongoing research activity in the Netherlands directed to end of life issues.

We would not wish to pretend that the Dutch approach to the regulation of euthanasia is perfect. We do believe, however, that an objective evaluation of the Dutch position requires consideration of what is happening in other countries with regard to euthanasia. This may lead us to the conclusion that although the Dutch situation may not be perfect, many things seem to be much worse in other parts of the world.

Contributors to this Issue

Maurice Adams

*University of Antwerp,
Belgium*

Margaret P. Battin

*University of Utah,
USA*

Luc Deliens

*Free University Brussels,
Belgium*

John Griffiths

*University of Groningen,
the Netherlands*

Joop van Holsteyn

*Leyden University,
the Netherlands*

Albert Klijn

*WODC, Ministry of Justice,
the Netherlands*

Paul J. van der Maas

*Erasmus University Rotterdam,
the Netherlands*

Freddy Mortier

*University of Ghent,
Belgium*

Bregje Onwuteaka-Philipsen

*Free University Amsterdam,
the Netherlands*

Margaret Otlowski

*University of Tasmania,
Australia*

Rob Schwitters

*University of Groningen,
the Netherlands*

Margo Trappenburg

*Utrecht University,
the Netherlands*

Cristiano Vezzoni

*University of Groningen,
the Netherlands*

Gerrit van der Wal

*Free University Amsterdam,
the Netherlands*

Heleen Weyers

*University of Groningen,
the Netherlands*