### SCIENTIFIC CONTRIBUTION

### Death by request in The Netherlands: facts, the legal context and effects on physicians, patients and families

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**Abstract** In this article I intend to describe an issue of the Dutch euthanasia practice that is not common knowledge. After some general introductory descriptions, by way of formulating a frame of reference, I shall describe the effects of this practice on patients, physicians and families, followed by a more philosophical reflection on the significance of these effects for the assessment of the authenticity of a request and the nature of unbearable suffering, two key concepts in the procedure towards euthanasia or physician-assisted suicide. This article does not focus on the arguments for or against euthanasia and the ethical justification of physician-assisted dying. These arguments have been described extensively in Kimsma and Van Leeuwen (Asking to die. Inside the Dutch debate about euthanasia. Kluwer Academic Publishers. Dordrecht. 1998).

**Keywords** Euthanasia · Physician-assisted suicide · The Dutch Euthanasia Law · Euthanasia consultants · Euthanasia Review Committees · Effects of euthanasia on physicians · Patients and families · Euthanasia requests and ethical/psychological conflicts · Medical friendship

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## Euthanasia and physician-assisted suicide in The Netherlands

The Dutch practice of physician-assisted dying (PAD) has reached a phase of integration since the early eighties of the previous century, when the Royal Dutch Society for the Advancement of Medicine (RDSM) came out in favor of the possibility of PAD in 1984. Before that date, since the seventies, a growing acceptance of this practice appeared in various court cases of physicians being accused of criminally ending the life of a patient. Before 1998, each case of PAD led to a criminal investigation by the police and ultimately was decided at a central level in the Justice Department, with a final decision by the Secretary of Justice. Five cases on PAD have been decided by the highest legal institution, the Hoge Raad, meaning High Council, leading to a further refinement in detail of the legal norms under which physicians could end the life of a patient without running the risk of criminal proceedings. All of these cases except for one ended with light and often suspended sentences for technicalities or to a verdict of not guilty. The exception, the last case, in 2004, concerned a verdict of a lower court that was upheld, because the patient in question, even though she suffered unbearably according to the physician and family, never had expressed a request to die.

The important fact to remember is that the focus in these court cases never has been the ending of life as a criminal act, as murder. Instead, the focus has been on the nature of medical participation at the end of life, with severely ill patients or patients with a terminal disease. From a normative angle the courts' orientation has been on *medical science and medical practice*: how physicians deal with sick patients at the end of their life and how they assist patients according to medical protocol and custom (Pans 2006).



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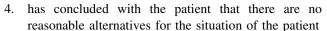
The developments in The Netherlands culminated in the acceptance of a law, effective since April 1, 2002, named: Review Procedures for the Termination of Life on Request and Assisted Suicide and Amendment of the Criminal Code and the Burial and Cremation Act. The law is a codification of previous jurisprudence, with one addition: the option of an advance directive with a request to end life in case of legal incompetence.

The basis of this law, often called the Euthanasia Law, is a distinction between interventions at the end of life that are called 'normal medicine' and those that are called 'not normal medicine'. Death in the course of a non-treatment decision, in the course of the alleviation of pain and suffering, including palliative sedation in case of refractory symptoms, are considered 'normal medicine', resulting in a 'natural death'. Euthanasia, physician-assisted suicide and ending of life without a request (with acronym LAWER) are considered 'not normal medicine'. Contrary to a general misconception, believing that PAD is 'legalized' in The Netherlands, it should be stressed that these interventions are still considered crimes. The subtle distinction of the euthanasia law is that each case of active help in dying may still be a crime, unless the intervention is carried out by a physician who has to report the act and will be evaluated on the basis of the conditions of the law. With the exception of the LAWER group: in the case of absence of a request criminal procedures will follow.<sup>1</sup>

The law also makes the previous central position of the criminal prosecution somewhat peripheral. Since 2002, the Euthanasia Review Committees (ERCs) have the final say in matters of PAD: they decide whether a case has been carried out with 'due care' or not. If not, then the case is referred to the criminal prosecution and the medical inspectorate, a kind of 'medical police'.

The 'euthanasia law' is by its nature physician-centered: in it the conditions are described under which *a physician* who reports his act will not be prosecuted. These conditions are that a physician:

- must be convinced that it concerns a voluntary and well considered request
- 2. must be convinced that it concerns unbearable and hopeless suffering of a patient
- 3. has informed the patient about the medical condition and the options



- 5. has consulted with at least one other physician independent of the case, who has seen the patient and has given his conclusions in writing with respect to the above conditions and
- has carried out the life ending intervention or assisted suicide in a medically correct way

The life ending intervention must be reported to a local medical officer and extensive forms and medical reports for evaluation must be made available for the ERC's.

The Dutch government has been intimately involved in the process of accepted euthanasia. It has had the audacity or expediency, depending on how one chooses to qualify this choice, to organize costly national research programs to find out 'how Dutch people die', in what ways, where and by what measures and to evaluate the legal and medical professional rules and regulations. About every 5 years since 1990 these programs are carried out and allow broad reflection on the quality of care at the end of life (1990, 1995, 2001, 2005). They also serve as checkpoints for undesirable developments such as (the fear of) a 'slippery slope' for PAD. So far, this fear has proven not to be realistic, based on research over these 15 years (Van Alphen et al. 2010, 263).

### Procedures to evaluate euthanasia and physicianassisted suicide

In the mean time, between 1990 and 1997, much attention has been paid to develop and institutionalize measures to safeguard against undesirable practices. The focus of these safeguards is both on the period before PAD and after. Consultations by 'independent medical doctors', being unfamiliar with and not involved in the case, take place before PAD, evaluations by the ERCs afterwards. A pragmatic approach has been made to have a 'medical consultation' before the act as opposed to a judicial one, because of the necessity for a consultation within a time frame of days rather than weeks. And in the second place, it was considered to be contradictory to involve the law in checking whether an intervention that in principle had not taken place and was criminal in nature, should be given 'the green light'.

From 1997 on, the RDSM, with broad financial support of the government, has established courses for potential professional consultants to physicians who have decided to honor a request to help to die. Nowadays, there are professional consultants in all regions of the RDMS, numbering more than 600 individuals. They are experienced physicians, most of them are family physicians, reflecting



<sup>&</sup>lt;sup>1</sup> The presence of the LAWER group has been the reason for much criticism of the Dutch end-of-life practice. It should be noted that this subject itself, even though it is very important, is not the focus of this paper. Clearly these cases are not in conformity with the Dutch conditions of acceptable PAD. The main justification of the physicians has been the impossibility to communicate in situations of extreme suffering and a shortening of life of hours or days at the most. See Pijnenborg (1995, pp. 81–88).

the high interest of this group in PAD from early on, and about 15% are hospital based clinicians and nursing home physicians, the latter a medical specialty in The Netherlands.

From 1998 on, there are also five Euthanasia Review Committees (ERCs), reflecting the number of judicial regions in The Netherlands. These are multidisciplinary committees, with three members: a lawyer, a physician and an ethicist, with nominated deputies for each discipline. These committees meet on a monthly basis to evaluate each case of PAD that has been reported, and they must evaluate and report back within a time period of 6 weeks. The delegation of the evaluation afterwards to a 'lay committee' has met both national and international resistance. The idea behind it was to increase the rate of reporting by including a physician, even though there was hesitancy to delegate the evaluation of a serious potential crime to others than the normal legal institution for prosecution. The idea was to 'put the criminal law at some distance', leaving the possibility of criminal procedures in principle open.

The ERCs have now functioned for more than 10 years. They publish annual reports to render account of their activities and to fulfill one of the basic requirements behind all Dutch regulations concerning euthanasia (E) and physician-assisted suicide (PAS), to make the practice transparent and to take PAD out of a 'grey area', without the veil of previous ignorance that still persists in medicine other than The Netherlands, Belgium and Oregon. This veil of ignorance does not imply in any way a low level of public discourse: on the contrary. But nowhere has a country other than The Netherlands made a scientifically valid investigation concerning an overall view of the ways in which people die, in order to discover the extent of legal or illegal practices.

In their annual reports the ERCs describe cases that were found to be problematic or 'without due care', mostly on technical grounds, but also, and more interesting, cases where they focus on the absolute nature of the limits of possibilities for E and PAS under the law. This focus is by definition on individual cases, weighing the individual facts of a case and finding out if these specific facts lead to conclusion of a careful procedure, or not. These decisions have a certain guiding meaning and function as precedents in the decisions of these multidisciplinary committees.

The essence of 'precedents' is formulating answers to individual cases with a complexity that is answered on an individual basis, but also establishing validity in conformity of the law in other comparable cases. That is the meaning of jurisprudence in law. Examples of 'corrective' decisions concern for example issues of adequate consultations, sometimes not independent enough or the question of (the absence of) a well defined treatment relationship of the physician who carries out the final intervention, or the

use of pharmaceutical substances other than the officially prescribed ones. Examples of shifts in 'acceptable euthanasia' can be observed in cases where patients lose full consciousness in the end and yet the life ending takes place, because there is no uncertainty or hesitance about the nature of unbearable suffering or the desire of the patient. Another example, one that is certain to cause much reaction, concerns the acceptance of PAD in cases of 'early Alzheimer's', where after unusually long drawn out procedures the request of a patient has been accepted as coming from a competent person, while the unbearable nature of the suffering is also established without doubt for the involved physicians.<sup>2</sup>

Over all these years, from 1998 through 2008, 38 cases have been deemed to be 'without due care'. Testifying to the scrutiny of the committees and their rather rigid evaluations is the fact that in none of these cases the legal authorities have seen adequate ground for criminal proceedings. So it seems, the regulations and procedures work well. The present conservative government has opted to maintain the existing procedures and resist any attempt to extend E and/or PAS to other groups of patients or to elderly without a disease but with a request to end life, the so-called people who 'suffer from life', having lost the desire to live on.

### The effects of this practice on physicians, patients and families

Only in countries where a practice of euthanasia and/or PAS is allowed, is open and transparent research with a claim of validity is possible.

In the past and current debates on euthanasia one type of argument focuses on the negative effects of such a practice on families, care givers and society, the so-called consequentialist arguments, with a focus on the negative effects for patients, families and physicians. In the first pilot study on the effects of PAD on families in 1990, Carlucci-Ciesielski and I discovered in families we interviewed an extremely positive feeling about the active end of life of a

<sup>&</sup>lt;sup>2</sup> The 'extension' of acceptable euthanasia to 'early Alzheimer's patients', as reflected in the Annual Reports of the ERCs, undoubtedly will be judged by some as a sure sign of 'the slippery slope'. However, this extension can be seen also as a correct and nuanced interpretation of the legal conditions in particular individual cases after a long process of evaluation by geriatricians and psychiatrists. Denying PAD in these circumstances with that particular diagnosis of *early* Alzheimer's, with competence, might be seen as unlawful discrimination. It should be clear that this paper does not address the issue of life-ending of severely deformed newborns: under Dutch law that intervention cannot be seen as euthanasia, because euthanasia is by definition the ending of life after a request of a competent person. Newborns are not competent and do not request an end to life.



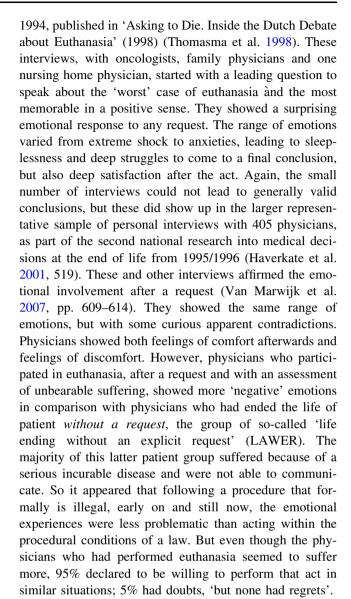
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family member (Ciesielski and Kimsma 1994). There was one exception. In a family where a young father died through PAD, the mother excluded the young children from the process of decisions leading up to the intervention. Not only the physician had doubts about the propriety of that 'silence', but the spouse felt that this 'secret in the family' made the acceptance of this death more difficult. This example did not constitute an argument against the euthanasia in itself, but was more of an argument against a lack of transparency and openness in the various steps.<sup>3</sup>

The small number of the families we interviewed in the pilot project was not representative and made it difficult to generalize the conclusions of an overall very satisfying intervention, with grief but also feelings of being content that further suffering had been spared. In a larger retrospective project Swarte et al. (2003, p. 189) compared grief in two groups of next of kin of women who died of a gynecological cancer in the period of 1992 through 1997 in the Academic Center of the Utrecht University. The various 'instruments' they used to assess the stages and intensity of grieving showed significantly less grief in the group of PAD. Even though the editors of BMJ choose a caption reading 'Bereaved people cope better after euthanasia than natural death', the authors are extremely careful and refrain from that conclusion. But they point out that E and PAS make it possible to come to terms with the death of someone because of the possibility of 'anticipatory grief' and an opportunity to discuss impending death freely and extensively in an open atmosphere with the patient that will die.

#### **Euthanasia hurts**

There has also been research on the effects of PAD on physicians, and to a lesser extent on what it means for other care givers such as nurses and families. The first pilot interviews were by Thomasma, Kushner and Kimsma, in



At that time the authors of the article were surprised at this difference in effects between the 'euthanasia group' and the LAWER group, but these unexpected data were not a reason for deeper reflection: 'It is striking that ending a patient's life without an explicit request later evoked feelings of discomfort (burdensome, emotional or a heavy responsibility) less frequently than did performing euthanasia or assisted suicide.'

We believe that this difference between expectation and outcome calls for further analysis and explanation. We are convinced that this difference in emotional reaction towards a request for euthanasia is essential for understanding what a request means in medical and psychological terms. Our thesis and conclusion is that deeper emotional reactions reflect a different relationship in cases of E and PAS in comparison with the doctor-patient relationship of LAWER, but also in comparison to normal care, even with patients with a terminal disease.



<sup>&</sup>lt;sup>3</sup> One of the reviewers pointed out a presumed comparability between the dangers of sex in the physician-patient relationship and the risks of euthanasia. Both issues, it is claimed, are based on a seduction that may promote behavior beyond the ethos of medicine. The drive for sex is controlled by Eros and the other, to help people die, by Thanatos, expressed as 'a drive to rid themselves (e.g. the physicians, GKK) of 'difficult' and undesired patients.' See Barilan (2003, pp. 460-463). In my view, this connection between sex and euthanasia, as euthanasia is practiced in The Netherlands, may not be entirely theoretical, but has no validity. The practice of euthanasia is open, transparent and evaluated, before and after the intervention. Patients are the prime movers of the process and each next step is initiated by patients, not by physicians. Cost concerns have no place, since patients are entitled to all possible palliative care. The motives behind claims of this nature are all based on anxieties and fears of 'slippery slopes' and a lack of trust in the medical profession. The Dutch democracy has chosen a different path.

# Requesting euthanasia and the physician-patient relationship

Physicians in The Netherlands are confronted with requests to help to die on the average 2 or 3 times a year. There are about ten times more requests than actual cases, because many people ask these questions just to come to some assurance of this option in the future. Requests for the near future from sick people are about 3 times more often than actual requests to be helped in a short while. Reasons for physicians to refuse in two out of three cases are: the presence of alternative treatments, the level of suffering, the lack of depth in a request, an incorrect assessment of the seriousness of a disease by the patient, the unilateral withdrawal of a request or: 'objections in a particular case or in general against PAD of a physician'. Each item in itself is a reason for further analysis. However, what these refusals have in common and what remains hidden in the sequential description of these reasons is the fact that each request starts a process of deliberation that has special qualities as compared to the interactions in the usual physician-patient relationship. That process of deliberation, the euthanasia discourse, has been the focus of research by American anthropologist Frances Norwood (Norwood 2009). She observed and participated in the work of 10 family physicians in Amsterdam, followed and interviewed their terminal patients. She concluded that a request for euthanasia changes not only the doctor-patient relationship, but also the relationships between patients and their families and friends. This change is a deepening and strengthening of the emotional commitments and relations. The basis of this change in the physician-patient relationship lies in the commitment that a request implies: the possibility to have to end the life of a patient when suffering becomes unbearable and the patient persists in wishing to die. This commitment, with all respect, goes beyond the commitments of usual or normal care at the end of life. In fact, all aspects of usual care including palliative measures are implied, but there are additional aspects.

### Requests and conflicts

Being confronted with a request to end life creates conflicts for physicians and all others who are involved. Ending life is an inherently immoral intervention, a crime in all societies. As Buchanan states forcefully: 'if anything is wrong, *that* is wrong' (Buchanan 1996).

This conflict has at least two sources: a psychological and an ethical-philosophical source. The psychological conflict concerns a confrontation with mortality in a way that escapes the usual professional resistance to fears and anxieties when patients appear to have a terminal disease.

Patients and physicians both live in a culture of denial of death and medical technology is the instrument par excellence to realize that denial. But even though, according to Freud, there can be a rational acceptance of death, 'the unconscious' promotes behavior that clings to the idea of immortality (Freud 1957). Physicians have learned to counter emotions with professional distance and objectivity in order to be able to help patients accommodate to the realities of impending death. However, the appearance of fears, anxieties and sleeplessness after a request is testimony of the insufficiency of this professional self protection in this particular situation. Objectivity and professional distance are under a greater strain than in 'normal medicine' with terminal patients. Stein describes these processes of care in terms of continuous transference and counter transference, interactions that are not limited to psychoanalysis only. Caring implies a continuous identification with one's own motives as a care giver and the motives and desires of patients (Stein 1985, p. 21).

This process is largely unconscious and a physician's attitude can be seen as a mix of personal anxieties for death, motives for becoming a physician, personal and professional experiences with death and dying and the ethos of modern medicine. That attitude usually provides sufficient protection in caring for the dying. In general caring for terminal patients often implies a closeness and high level of emotional involvement and compassion. However, patients requesting help in ending their life break these barriers to anxieties down and force physicians to identify with their patients' suffering over the borders of their anxieties. In order to be able to help a patient die they need to become convinced in a rational way that the authentic answer to that suffering is an active ending of life. This implies a need to come closer to the patient who has expressed that request.

The necessity to come to a conclusion that the suffering of this particular patient indeed has become unbearable as a joint conclusion between physician and patient implies intimate knowledge of the patient as a person and a human being with a biography. This joint activity is keenly distinguished in the Dutch Euthanasia Law where it is stipulated that physician and patient together have come to a conclusion that, for euthanasia to be allowed, there is no other reasonable solution available. Suffering has many sides, but in essence two philosophical approaches can be distinguished: the empirical side of suffering and the hermeneutic side. Unbearable suffering does not only concern the empirical, physical symptoms or complaints and the loss of functions and independence. Essential for the evaluation is the hermeneutic aspect: what these symptoms and loss of functions mean to a patient as personal evaluations of that patient. In order to be able to perform that function a physician must know about the patient as a



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person, the patient's biography and the patient's context and balance of endurance and tolerance.

The second source of emotional conflicts for physicians who are confronted with a request to help someone die has philosophical and ethical roots. The principle objection against euthanasia is that ending a person's life goes against the grain of a fundamental prohibition: 'Thou shallt not kill'. In most civilized societies even the execution of killers is now prohibited, in conformity with this rule. In our culture, Christianity has been forced to reflect intensely on the feasibility of the absolute nature of this principle. The absolute interpretation conflicted with the desire to become the religion of the state, after Constantine the Great's conversion to Christianity in 325 AD. In order to become the religion of the state, the Church had to accept the killing of enemy soldiers in aggression. This option, however, has never been open to individuals, even in case of self defense, according to Saint Augustine (354-430). Thomas Aquinas ended the dispute in the twelfth century with his definition that 'taking innocent life is immoral at all times (Rachels 1987). Based on these convictions, taking innocent life in medicine appears to be a paradigmatic example of a fundamentally immoral intervention, as many still feel today (Pellegrino et al. 1988).

Nevertheless, throughout all time and ages, there has been a growing support among medical professionals and lay persons to allow the option to end the life of seriously ill people. There have been large euthanasia movements in the USA, Great Britain and Germany since the middle of the nineteenth century. In the ethical dilemma between prohibition and acceptance the onus is on the arguments to support this intervention. According to Buchanan, principle arguments against the intervention are the denial of a person's well being and dignity and the violation of his right to life. However, in case of serious illness, the disease already has taken a patient's wellbeing and dignity. And secondly, a right to life implies the option not to exercise that right any longer. That choice is entirely the individual's choice. That is essentially the meaning of autonomy, and from this conclusion it follows that autonomy is the fundamental argument to justify the taking of life. This position is reflected in Dutch jurisprudence and law: without a request there cannot be a justified euthanasia or physician-assistance in suicide.

However, autonomy is not the sole justification. A request by itself is insufficient justification: it would lead to a permissive system for which no physician has expressed support. The second fundamental argument is found in the experience of compassion. This experience is not an individual's quality but the expression of a relation. To respond to unbearable suffering and breaking a fundamental law, is only possible when there is a relation that makes it possible. Being able to end the life of a patient implies the

existence of a physician-patient relationship with different qualities than in 'normal medicine'.

It is important to realize that this relationship is reciprocal and mutual. This reciprocity has been observed by consultants and discussed in interviews with physicians (Obstein et al. 2004, p. 223). One of the signs of this mutuality is the fact that the final decision to go ahead with E or PAS is taken after a process in which patient and physician come to a joint shared conclusion that suffering indeed has become unbearable and hopeless. This shared conclusion does not come 'spontaneously'. It is the result of communication about medical options and how patients experience these options in the light of the progress of the disease, their vision about how much they 'choose' to endure and the quality of life. There may be and often are differences of opinion in the possibilities of palliative measures. As Norwood has shown, physicians tend to wait until patients initiate 'the next steps in the sequence of events leading to E and PAS. Patients sometimes need to wait until they have convinced 'their physician'. They do so, out of respect. Patients very well know that what they ask of a physician is the ultimate of what human beings can ask each other.

Recent research with patients who request for E or PAS has shown a difference in focus on suffering between physicians and patients (Pasman et al. 2009). Physicians tend to focus on physical symptoms such as pain and chronic fatigue, patients stated that the pain did not make their suffering unbearable, but seemed 'mainly to consist of non-physical suffering, such as (fear of) dependence, no longer being able to participate in normal daily life, or mental suffering, because of deterioration'. Physicians also would focus on what the authors describe as 'coherence': a difference in expected and actual behavior of a patient, such as reading a book, or being able to open the front door in order to welcome the physician. During the process of euthanasia these differences either are leveled out or result in a refusal to a request.

### A different relationship: 'medical friendship'

It is important to reflect on the issue whether a relationship of that type fits customary conceptions of the doctor–patient relationship. Clark and I reintroduced the notion of 'medical friendship' to describe the different relationship in case of a euthanasia process (Clark and Kimsma 2004). We proposed Aristotle's notions of friendship to qualify that type of relation (Aristotle 1999, book eight). What Aristotle describes in the Nicomachean Ethics is friendship based on either pleasure, utility or virtue. 'What is key for the physician and patient is the concept of reciprocal love or similar virtue that makes the category of virtue



necessary for a complete friendship. One important aspect of this reciprocity is that no one who is a complete friend would ask the other to do something morally base and contrary to virtue. Doing so would demonstrate that the relationship never was or is no longer founded on shared virtue; it has become one of utility' (Clark and Kimsma 2004, p. 64). The qualification of friendship for the patient physician relationship is not alien to medicine: Linda and Ezekiel Emanuel have proposed a 'deliberative model' in which the physician acts 'as a teacher or friend, engaging the patient in dialogue on what course of action would be best' (Emanuel and Emanuel 1999). Their description gives maximum room for patient values, but it lacks space for the physician's values. What is essential to realize is that the patient must respect what is asked of the physician as much as the physician must come to terms with what the patient requests, in a process of mutuality with a final interpersonal agreement.

#### **Concluding remarks**

My intention has been to show that a request for euthanasia or physician-assisted suicide has emotional effects on patients, families and physicians. The focus has been on physicians and patients with the aim to analyze why a request evokes such emotional responses. Research attests to the depth of what it means for a physician to end the life of a patient. These deeper unsettling responses, however, are reasons for deeper relationships than in daily medicine with its focus on healing. They serve as conditions to be able to assess the unbearable suffering of patients and in the end to come to a joint conclusion that this suffering has been enough.

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