In vertrouwen. Normatieve beschouwing over euthanasie, dementie en de schriftelijke wilsverklaring

Pijnakker, P.

Summary in English

On 1 April 2002, the Dutch *Law on Termination of Life on Request and Assisted Suicide* (hereinafter to be referred to as 'the Law' on euthanasia) came into effect.[1] The content of the law had been influenced by case law from the beginning of the 1970s. By codifying norms already in place, the new euthanasia law (2002) would change little about existing practices, with the exception of the normative framework for unconscious patients and the installation of multidisciplinary review committees. In order to remedy the oppressive situation faced by a patient suffering unbearably from dementia while guaranteeing greater legal certainty for doctors, legislators intended to provide a legal basis for the special situation of a patient who had drafted a written declaration of intent, but had subsequently become unresponsive. For that specific situation, Article 2 paragraph 2 of the Law allows the doctor to rely on the previous written declaration of will, whereby the due care requirements of Article 2 paragraph 1 of the Law counts on *mutatis mutandis*, meaning it is also applicable, but with some changes due to the specific case. The starting point is both extra caution and the greatest possible objectivity in the assessment of the patient in his situation of unbearable suffering. In 2016, for the first time, a specialist in geriatric medicine had to answer to the disciplinary Court and Criminal Court after performing euthanasia on an unresponsive, deeply demented 74-year-old woman. In response to this case, this dissertation looks for more distant backgrounds in which medicine, law and ethics are combined in an interdisciplinary framework.

The twofold research question is:

1 What meaning is hidden behind the concept of the *mutatis mutandis* application of the due care requirements as referred to in Article 2 paragraph 2 of the *Law on Termination of Life on Request and Assisted Suicide* in accordance with the legal history, at the reviewing (disciplinary) authorities and in medical practice?
2 How can Article 2 paragraph 2 of the *Law on Termination of Life on Request and Assisted Suicide* as an acceptable and defensible normative framework for life-ending actions by doctors at the boundaries of the domain covered by the Law?

The aim of this thesis is to identify problematic aspects (content and meaning) of the *mutatis mutandis* application of the legal due care requirements and to organize them, to contribute to a normative-ethical framework and the reflection on it, and to contribute to the (scientific) discourse on euthanasia in patient's in an advanced stage of dementia.

Chapter 1 describes and analyzes the history of the Law of euthanasia and the case law leading to the Law in a normative sense. The Law concerning termination of life on request and assisted suicide have been established under criminal law. The basis for this

[1] In Dutch: 'Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding'.

was Article 40 Criminal Code: force majeure in the form of a state of emergency consisting of a conflict of duties, in which a doctor finds themselves when confronted with a current euthanasia request from a hopeless and unbearably suffering patient. The most important conclusion from history is that the Law was almost entirely a codification of norms that already applied before, mainly on the basis of judgments of the Supreme Court in the cases Postma (1973), Schoonheim (1984), Chabot (1994) and Brongersma (2002). In setting standards, the judge has always been guided by the medical profession, the current medical scientific insights, and standards in medical ethics.

In 2002, the Supreme Court formulated a general restriction: the patient's suffering must be based on a psychological or somatic medical classified disease (classification requirement).

In chapter 2, common threads of the legislative process are explained on the basis of a more or less chronological treatment of the parliamentary consideration of the Law. In the legislative process, the concept of *mutatis mutandis* application is also developed, which refers to euthanasia of an unresponsive patient on the basis of a (competently drawn up) written statement of will, who can no longer repeat his explicit oral request for termination of life. The bill was adopted by amendment with the aim of increasing legal certainty for doctors, formulated in Article 2 paragraph 2 of the Law, including the term *mutatis mutandis*. Article 2 paragraph 2 of the Law reads:

> *If the patient aged sixteen years or older is no longer capable of expressing his will, but prior to reaching this condition was deemed to have a reasonable understanding of his interest and has made a written statement containing a request for termination of life, the physician may carry out this request. The requirements of due care, referred to in the first paragraph, apply mutatis mutandis.*

As this Article is of a modifying rather than a codifying nature, the scope and the application of that provision for doctors has been vague from the beginning.

Chapter 3 analyses how reports of euthanasia (period 2012-2020) by the Regional euthanasia Review Committees (RRC) have been assessed with regard to the core aspects of Article 2 paragraph 2 of the Law: the written declaration of intent, the (un)responsiveness of the patient, and the hopelessness and unbearability of suffering. The analysis of these characteristics in 14 examined judgements shows a rich and detailed overview with an often high degree of unity between the review committees, the (executive) doctor, and the SCEN-doctor. With regard to the core aspects, there may be an intrinsic field of tension in the system of assessment. So there may be differences of opinion between what the doctor has indicated in the report, and the vision and assessment of these aspects by the review committees. These differences of insight may have consequences for the assessment of whether the doctor in an advanced dementia case has acted in accordance with the due care requirements in a specific case.

The written declaration of intent in some judgements has been completely and literally described, but in most cases according to it's nature. As a result, it is difficult to determine how these written declaration of intent has provided for the situation of unbearable suffering. It follows from seven of the 14 examined judgements that the written declaration of intent had a supporting role in the contact between doctor and patient, without fulfilling a substitute function within the meaning of Article 2 paragraph 2 of the Law.

With regard to the hopelessness of suffering, it is striking that the review committees relate this uniformly to the underlying diagnosis of the patient, without differentiating on patient characteristics. A specific description is given to the unbearability of suffering, which is expressed in an individualized and detailed manner in all published judgments.

It is noticeable that the SCEN-consults[2] – as far as they are expressed in the judgments of the RRC – predominantly show a focus on physical (medically objective) aspects of suffering. This is likely explained by the fact that contact between doctor and patient is consulting in nature, meaning that the SCEN-doctor has fewer opportunities or less time to come to the conviction that the suffering of the patient is unbearable. Furthermore, it is striking that aspects of disillusionment also receive an interpretation often linked to physical suffering and are less connected to mental problems.

The know-how of the medical profession regarding an incapacitated patient with whom no meaningful communication is possible anymore, seems even more decisive for the assessment of the admissibility of life-ending actions compared to a patient who is able to communicate meaningfully. At the same time, it is striking that in some cases may be differences of opinion between what the doctor has indicated in the report, and the vision and assessment of these aspects by the review committees.

Chapter 4 sets out the full legal process and the impact of the Arends-case. Arends, a specialist in geriatric medicine, granted euthanasia to an unresponsive, deeply demented 74-year-old woman. In doing so, she complied with the written declaration of intent previously drafted by the woman. As a result, this doctor was accountable to all reviewing (disciplinary) boards, including the Criminal Court.

In the judgment of the Court and the Supreme Court in the Arends-case, at least three normative themes manifest themselves: the scope of the interpretation of the written declaration of intent, the verification requirement of the death wish by the doctor, and the so-called contraindications.

Regarding the written declaration of intent of the unresponsive patient, the judgments of the Court and the Supreme Court in the Arends-case state that the doctor was allowed to rely on the patient's written declaration of intent by finding out the intentions of the

[2] In Dutch: Steun en Consultatie bij Euthanasie in Nederland.

patient. In doing so, the doctor must take into account all special circumstances of the case and not rely only on the literal words of the request.

Regarding the verification requirement of the (coherent) death wish in a deeply demented patient, the Court clarifies the doctor's task by expanding 'coherent' to 'clear and coherent and therefore meaningful'. In the opinion of the Court, it would be contrary to the spirit of the Law if a person who had become unresponsive was then able to revoke a legally valid euthanasia request previously drafted by him or her. The specific circumstance of unresponsiveness implies that oral verification of the both the wish for death and the unbearable suffering is not possible. This interpretation of the court is sensitive within the profession of doctor's, especially if the patient no longer understands the concepts of 'death' and 'life' or no longer has a memory of the request.

Regarding contraindications, it is important to note that any 'signs' from the patient that they no longer wish for euthanasia do not *necessarily* have to be associated with their previously expressed wish to die. The doctor must note inconsistencies in the patient's behaviour or expressions suggesting that the actual condition of the patient does not correspond to a condition of unbearable suffering as provided for in their written request. Contraindications can therefore exist with regard to suffering, but to a much lesser extent with regard to the will or request for which the substitute written euthanasia request serves. Of course, statements indicating a modified will must be respected at all times, but the doctor does not have to note any contraindications if the patient can no longer express their will coherently at that time. The possible relevance of such 'signs' are subject to interpretation by the medical-professional. The Court (and the Supreme Court) upheld the validity of the original death wish, rejecting the Public Prosecutor's assertion that the alleged ambiguity of the statutory regulation meant the willful death wish could be over-ruled.

Chapter 5 is the introduction to the qualitative-empirical research (focus groups) and describes successively the reason, design, working method, and implementation of the focus groups and the analysis process (thematic analysis) afterwards.

Participants were general practitioners and geriatric specialists experienced in written euthanasia requests from people with dementia who are becoming increasingly unresponsive. The central question was how doctors deal with written euthanasia requests from patients in an advanced stage of dementia. The sub-questions were: what are the experiences and views of doctors who commonly deal with these patients? How do doctors give content and form to the *mutatis mutandis* application of the due care requirements? What do doctors in the aforementioned situation consider to be a justifiable, professional, and convincing *mutatis mutandis* application of these criteria?

In chapter 6, the findings of the participating physicians in the focus groups are described in detail. A variety of themes provide insight into the experiences, the patients in their consultation rooms, their entourage, and in particular on the question of what meaning they implicitly or explicitly give to the *mutatis mutandis* application of the due care requirements. What doctors mean by *mutatis mutandis*, though difficult to define, is integral to the nature of clinical care in this sensitive period.

Mutatis mutandis appears to be a referring concept, with the doctor-patient relationship as a concrete starting point, and a less concretely defined point of destination. Of primary concern here is the professional relationship between doctor and patient, which refers to a predetermined direction in which contemporary policies and boundaries are determined. Subtle boundaries vary in every contact due to differences in language, origin, biography and philosophy of life, normative frameworks and history.

Euthanasia of an unresponsive patient on the basis of a written declaration of will is allowed if their written declaration of will for euthanasia can be understood in relation to their life course, there is a convincing situation of clearly perceptible unbearable suffering and/or disillusionment, and when the quality of the relationship between doctor and patient is sufficiently substantial.

In chapter 7, the research questions and the normative implications based on the findings from the preceding chapters 1 to 6 are evaluated with the aim of providing further details and meaning for the *mutatis mutandis* application of the legal due care requirements. A comprehensive overview of the issues around written euthanasia requests by advanced dementia patients was obtained by combining interdisciplinary perspectives (medicine, law, and ethics) and various research methodologies, including historical analysis of the legislative process and of the judgments of the RRC, in-depth analysis of the Arends-case, and empirical focus group research. This has led to the following normative considerations.

The moment of both handing over and of accepting a written euthanasia request is normatively a key moment: *in confidence*. The normative value of Article 2 paragraph 2 of the Law is that it enables, both legally and practically, the doctor to guide an unresponsive patient in an advanced stage of dementia *up to and including* the last phase of life and to honor their given norms, values, and history. At the basis of this concept is the professional relationship between doctor and patient in which certain boundaries are established. These subtle boundaries differ between both doctor and patient due to language, origin, biography and philosophy of life, normative frameworks, and history.

It can be thus stated that the *mutatis mutandis* application is the weight of specific facts and circumstances, which is determined first by a written declaration of intent for euthanasia, secondly by a convincing situation of clearly perceptible unbearable suffering, and thirdly

by the preferable existence of a 'close and comfortable relationship' between doctor and patient, with tangible references from a patient's life, their contextual evaluation confirmed by and in their personal environment. This makes it possible to adhere to the concept of the *mutatis mutandis* application and to Article 2 paragraph 2 of the Law, making a proposed change to the law unreasonable.

Given the subjectivity of the *mutatis mutandis* application, there is no set of general rules providing guidance on life-ending actions within the context of Article 2 paragraph 2 of the Law. The weight of specific facts and circumstances in an individual case determines and standardizes whether an unresponsive patient can be provided with euthanasia on the basis of a written euthanasia request. *Mutatis mutandis* application of the due care requirements can here play a role insofar as recognition of both the specific position of the completely unresponsive patient and their unbearable suffering prove possible.

Special attention is needed for the methods used in determining the (un)responsiveness of patients with dementia, the uniform assessment of complex euthanasia cases by the Regional euthanasia Review Committees (RRC), the legal elaboration of stepped involvement of the disciplinary judge and the Public Prosecution Service (OM), the training and education about advanced dementia with regard to end-of-life care within the medical and SCEN-doctor training programs, and the Expertisecentrum Euthanasie. *Mutatis mutandis* application is rooted in a specific problem, which is at once so consistent as to be found in the investigated sources and to also be a candidate as a question for, for example, thematic meetings on euthanasia and advanced dementia. These themes offer a view for further development and therefore also for future research.