

# When suffering becomes unbearable

Perspectives of Dutch patients,  
close relatives and attending physicians  
in a request for euthanasia

Marianne Karin Dees

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‘You matter because you are you,  
and you matter to the end of your life.


We will do all we can  
not only to help you die peacefully,  
but also to live  
until you die’

Dame Cicely Saunders



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‘De arts hoeft geen romans te  
lezen; hij beleeft ze’

Karl Marx



# *Chapter 1*

General introduction

Marianne K. Dees

## Suffering in end-of-life situations

One main goal of medicine is relief from suffering.<sup>1</sup> Alleviation of suffering is crucial in all of medicine, especially in the care of patients with incurable illnesses. Suffering cannot be treated unless it is recognised and diagnosed.<sup>2</sup> Diagnosing suffering requires a holistic approach that fits with the philosophy of palliative care. The physician must pay attention to the multifunctional needs of the terminally ill to better their quality of life and relieve suffering.<sup>3</sup> Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness. This necessitates preventing and relieving suffering by means of early identification, followed by impeccable assessment and treatment of pain and other problems, including the physical, psychosocial, and spiritual ones.<sup>4</sup>

We must view the needs of palliative care patients within their cultural, temporal, and social contexts to understand why, despite optimal palliative care, suffering becomes unbearable to the point that the patient requests euthanasia.<sup>5</sup> Are physicians entitled to help end the suffering of severely ill patients by ending their lives? This debate has been ongoing since ancient times. Euthanasia, from the Greek *εὐθανασία* meaning ‘good death’, refers to the practice of intentionally ending a life in order to end pain and suffering. In the Graeco-Roman world, a doctor was sometimes called in to assist in voluntary death, a role that was not forbidden by the Hippocratic oath.<sup>6</sup> In the 1970s, the first euthanasia test cases broke social taboos in countries with strong Christian traditions. The patients’ autonomy and the awareness among medical professionals about the limits of medical care had come to the fore.<sup>7</sup>

## A narrative about unbearable suffering

*Autumn 1990: a young man aged 21, diagnosed with a progressive testis carcinoma, asked his GP about his willingness to perform euthanasia. The GP had never been willing to end a life at a patient’s request. However, watching the fast physical deterioration of this youth, whom he had assisted in birth, convinced him that there was no other reasonable way to end the suffering. He asked his GP trainee (doctor Dees), who was at that moment working in the practice, to take the role of the second physician. She witnessed weekly for 2 months how cancer took possession of this young man’s body. The terminal phase was complicated by an ileus, a smelling open abdominal wound, and cervical paralysis. Both physicians knew that the young man with his vivid and optimistic mind was in a situation of unbearable suffering. It lasted until almost complete paralysis with the first signs of speech impairment before the patient himself came to acknowledge that he was in a situation of unbearable suffering.*

This narrative should be seen against the background of the Netherlands in the

early 1990s. In those days, the desire of incurably ill patients to have a say about their own death was becoming more and more acute. Euthanasia and physician-assisted suicide were not yet legalised, and physicians had to hand over each case to a state authority to be judged, in the hope that the case would be declared free from prosecution. The palliative care knowledge of GPs was pivotal and their role in palliative homecare was under discussion.<sup>8</sup>

The story of the young man underlines the subjectivity of unbearable suffering. In this case, the physicians judged the suffering unbearable before the patient experienced it. This contrast elucidates the emotional impact on the involved physicians and the complexity of the GP's tasks in end-of-life situations. The complexity depends on many things, including the patient's characteristics, the extent of the patient and GP's mutual history, the required specific medical knowledge, the moral dilemmas, the serious workload, and the ability to make decisions together.

This case of unbearable suffering highlights two important ethical principles underlying the Dutch euthanasia act: the patient's autonomy, one of the most respected ethical principles of modern western health care, and the physician's compassion.<sup>9</sup>

## **Respect for patient autonomy, end-of-life choices, and euthanasia**

In countries where EAS (euthanasia or physician-assisted suicide) is legal, respect for patient autonomy is one of the important underlying ethical principles. *Autonomy* literally means 'self-governing' or 'self-legalisation'. In ancient Greece, *autonomy* had a political dimension. The modern account of autonomy first of all refers to individual autonomy. Respect for autonomy means respecting the self-determination of a morally significant entity – a person. In the early 1970s in the Western world, while continuous medical developments generated great expectations of medical health care among the public, the widely accepted authority of the medical profession came under serious attack and raised expectations of greater autonomy.<sup>10</sup> The availability of palliative care and improved information allowed patients and family carers to exercise autonomy and to make end-of-life choices.<sup>11</sup> This challenge has been embodied in the progressive enumeration of patient rights, especially the right to refuse medical care and life-sustaining treatment, and public discussions about the right to die are ongoing.<sup>12</sup>

The contemporary meaning of autonomy is interwoven with the 'self' and 'individuality'. To some extent, this has become a moral cornerstone in Western thinking. This sense of the moral status of the individual has emerged through a

gradual paring off of the individual from established hierarchies of authority such as clan and class, church and state. Western health care and the patient–physician relationship are examples of an established hierarchy in which, at least now, we see consensus about an ethic of patient autonomy instead of medical paternalism.<sup>10</sup>

The full picture of where respect for autonomy fits in an account of the person is complex in the context of end-of-life care, and especially so in a request for EAS. Thinking about the end of life and respecting patients’ autonomy raises issues concerning physicians’ autonomy, rights, obligations, and duties, as well as the autonomy and rights of relatives and closely involved others. Respect for patients’ autonomy in the context of end-of-life decision-making requires a physician who is willing to place patients at the centre of decision-making, is willing to empower and help them to make informed choices about end-of-life preferences.<sup>11</sup> Respect for autonomy in the context of lawful euthanasia means that those involved are enabled to find a way to live and die that reflects the spirit of their life stories.<sup>13–15</sup>

## Unbearable suffering and legalisation of euthanasia

Patients in many countries confront their attending physician with a request for EAS to end hopeless and unbearable suffering. Only in Oregon, Washington State, Montana, Switzerland, Belgium, Luxembourg, and the Netherlands can such requests be legally granted, and then only on condition that certain criteria are adhered to. In countries where EAS is legal, the physicians’ freedom of conscience is guaranteed: they can always refuse a request.<sup>16</sup> In the Netherlands, the *Dutch Termination of Life on Request and Assisted Suicide (Review Procedures) Act* has regulated EAS since 2002.<sup>17</sup> The act states that EAS can be legally performed if the attending physician acts in accordance with six criteria of due care (Box 1).

### Box 1 Criteria for euthanasia or physician-assisted suicide

Euthanasia or physician-assisted suicide legally requires that the six criteria for due care of Article 293, paragraph 2, of the Dutch Penal Code<sup>5</sup> are met.

The treating physician must:

- a. Be convinced that the patient’s request is voluntary and well-considered
- b. Be convinced that the patient’s suffering is unbearable and hopeless
- c. Inform the patient about his/her situation and prospects
- d. Be convinced, as the patient must also be, that there is no other reasonable solution for his/her situation
- e. Consult at least one other independent doctor, who must see the patient and give his/her written opinion about whether the first four criteria have been satisfied
- f. Use all due care in terminating the life or assisting in the suicide

The second criterion of due care, i.e. the assessment of unbearable suffering, is essential in the Dutch euthanasia procedure<sup>18</sup> and is the crux of the discussion



around EAS.<sup>19</sup> ‘Unbearable suffering’ has not yet been clearly defined, and those involved might interpret it differently.<sup>20,21</sup> When requests for EAS are refused, patients and attending physicians differ most often in their view about whether the suffering is unbearable (35%). The Dutch review procedure seems to concentrate on the criterion of unbearable suffering and on procedural issues. For requests that the Assessment Committee judges should be refused, the condition of unbearable suffering is their most mentioned reason.<sup>22</sup>

In 1998, Beijk<sup>23</sup> described the necessity of shedding light on the factors that make suffering unbearable in the context of a request for EAS. In 2000, Kimsma<sup>24</sup> published a conceptual framework to describe suffering, as a tool for making an independent consultation of the Support and Consultation on Euthanasia in the Netherlands (SCEN) type transferable. In 2009, the Ministry of Public Health, Welfare and Sport published a model for reporting EAS.<sup>25</sup> These aids are based on a medical frame of reference, and there are no data about their practical implications. In addition, there is no evidence-based knowledge, in the context of a request for EAS, about the perceptions of the suffering of patients, their relatives, their attending physicians, and the independent consultants or about how they come to a decision about the performance of EAS.

## Objectives of this thesis

The aims of this thesis are 1) to gain empirical insight into the concept of ‘unbearable suffering’ in those situations where there is an explicit request for EAS, from the point of view of the patient, the closest relatives, the attending physician, and the independent consultant; and 2) to come to an understanding of the decision-making in a request for EAS.

## Research questions

1. What are the current views on the suffering of patients in the context of a request for EAS?
2. What are the constituent elements of the suffering of patients with a request for EAS?
3. What makes suffering unbearable according to the patients?
4. How do those involved in a request for EAS come to a decision, and how can decision-making be optimised?
5. What are the perspectives of those involved in a request for EAS on unbearable suffering when there is agreement about unbearable suffering and performance of EAS?
6. What does the use of modal verbs by those involved in a request for EAS reveal about the interpretation of the concept of unbearable suffering and about the individual physician’s behaviour?

## Methods

Given the facts that unbearable suffering is an ill-defined concept and that there is no evidence-based knowledge about decision-making in EAS, we designed a qualitative explorative study to answer the research questions. Qualitative methods are appropriate to uncover and understand what lies behind any phenomenon that is poorly understood. Qualitative research is an interpretive approach aimed at reaching an in-depth understanding of human behaviour and the reasons that govern such behaviour. The use of rigorous qualitative research can help to bridge the gap between scientific evidence and everyday practice. Data collection methods used in qualitative research are sensitive to the social context.<sup>26,27</sup> They involve close contact between the research participants and the researcher. The narrative, person-centred, and holistic approaches of both end-of life decision-making and qualitative research are complementary.

In the first step, we conducted an integrative, systematic, literature review and identified the current views on themes and elements that constitute unbearable suffering in the context of a request for EAS. From the results of the literature review and with the experience of the principal investigator (both as a practising GP and as a SCEN specialist), we designed a topic guide for the in-depth interviews.<sup>28</sup> The prospective, face-to-face, in-depth interviews with patients who explicitly requested euthanasia, their closest relatives, and their attending physicians are the core of this study. During the in-depth, face to-face interviews, we encouraged the participants to describe how the request became topical, the constituent elements of suffering, what made suffering unbearable, and how the decision-making proceeded.

We used ATLAS.ti version 5.5 software to process the data.<sup>29,30</sup> We performed secondary analyses to answer the various research questions. Then we used the constant comparative method, a part of the grounded theory approach, to come to an understanding of unbearable suffering of patients with an explicit request for EAS and to gain insight in decision-making in EAS.<sup>31</sup> We avoided using pre-set categories and explored the data as a whole.<sup>32,33</sup> To compare the perceptions of unbearable suffering within cases, we performed a thematic secondary analysis of all interview data and the written reports of the independent doctors.<sup>34</sup> The codes, categories, and themes that emerged from our original analysis of the constituent elements of the patients' suffering formed our code book.<sup>35</sup> We compared these elements within cases with the aid of SPSS software. We used TextStat 2, a word frequency and collocation programme for the quantitative linguistic data analysis.<sup>36</sup> Additionally we started from the corpus material as the main source of information for this analysis in a bottom-up approach.

## Outline of the thesis

**Chapter 2** presents the results of the integrative literature review aimed to gain

information about the current definitions of ‘suffering’ and the motivations for EAS associated with ‘unbearable suffering’, as given by patients, healthcare professionals, and relatives (research question 1). It provided no general definition of unbearable suffering, but it did bring to light the various dimensions of suffering and the many different motivations for a request for a hastened death. It appeared that patients, healthcare professionals, and relatives present their own sets of motivations.

**Chapter 3** answers research questions 2 and 3. It contains the results of a qualitative analysis (constant comparative method) of the in-depth, face-to-face interviews of patients with an explicit request for EAS. The analysis shows that unbearable suffering is the outcome of an intensive process that originates in the symptoms of illness and/or aging. According to patients, hopelessness is an essential element of unbearable suffering. Medical and social elements may cause suffering, but especially when psycho-emotional and existential problems accompany suffering, it will become ‘unbearable’. Personality characteristics and biographical aspects greatly influence the burden of suffering. Unbearable suffering can only be understood in the continuum of the patients’ perspectives of the past, the present, and expectations of the future.

**Chapter 4** answers research question 4. It presents the results of a constant comparative analysis of the in-depth interviews with patients who explicitly request EAS, close relatives, attending physicians, and reports of the independent consultants. The main outcomes are that a patient’s request for EAS entails a complex process that demands emotional work from all the participants. The process is characterised by an intensive period of sharing information, relationship building, and negotiation to reach agreement. We came to the hypothesis that making decisions about euthanasia demands careful attention to shared decision-making and a proactive approach towards the participants’ preferences and values regarding the end of life, the needs of relatives, and the burden placed on physicians.

**Chapter 5** answers research question 5. It contains the results of a secondary thematic analysis of the in-depth interviews of patients with an explicit request for EAS, close relatives, attending physicians, and reports of the independent consultants in cases where the patient and physician have agreed about unbearable suffering and performance. There appeared to be a substantial resemblance of the patients’ existential, medical, and psycho-emotional themes with those of the other participants. Relatives reflected the patients’ views best in all the themes, and strikingly well in the existential theme. The attending physicians and independent doctors had little affinity with the elements of the socio-environmental theme, especially with the elements ‘being a burden’ and ‘prospect of going to a nursing home’. Independent doctors scarcely reported ‘nothing left to live for’ to the

## Regional Review Committees.

**Chapter 6** answers research question 6. Five clusters with in-depth interviews with patients, relatives, and attending physicians were quantitatively (TextStat 2) and qualitatively (bottom-up approach) analysed for the use of modal verbs. We conclude that the quantitative linguistic analyses confirm the findings of earlier qualitative analyses about the concept of unbearable suffering. The qualitative bottom-up analysis appears to be a way of gaining insight into the connection of language use to relational aspects of communication. We conclude from this that interdisciplinary research in the medical domain is worthwhile. Further, we believe that linguistic analysis can help optimise doctor–patient communication.

**Chapter 7** discusses the main findings of this thesis, considers the methods and limitations, and recommendations are made for daily practice, policymakers, and future research.



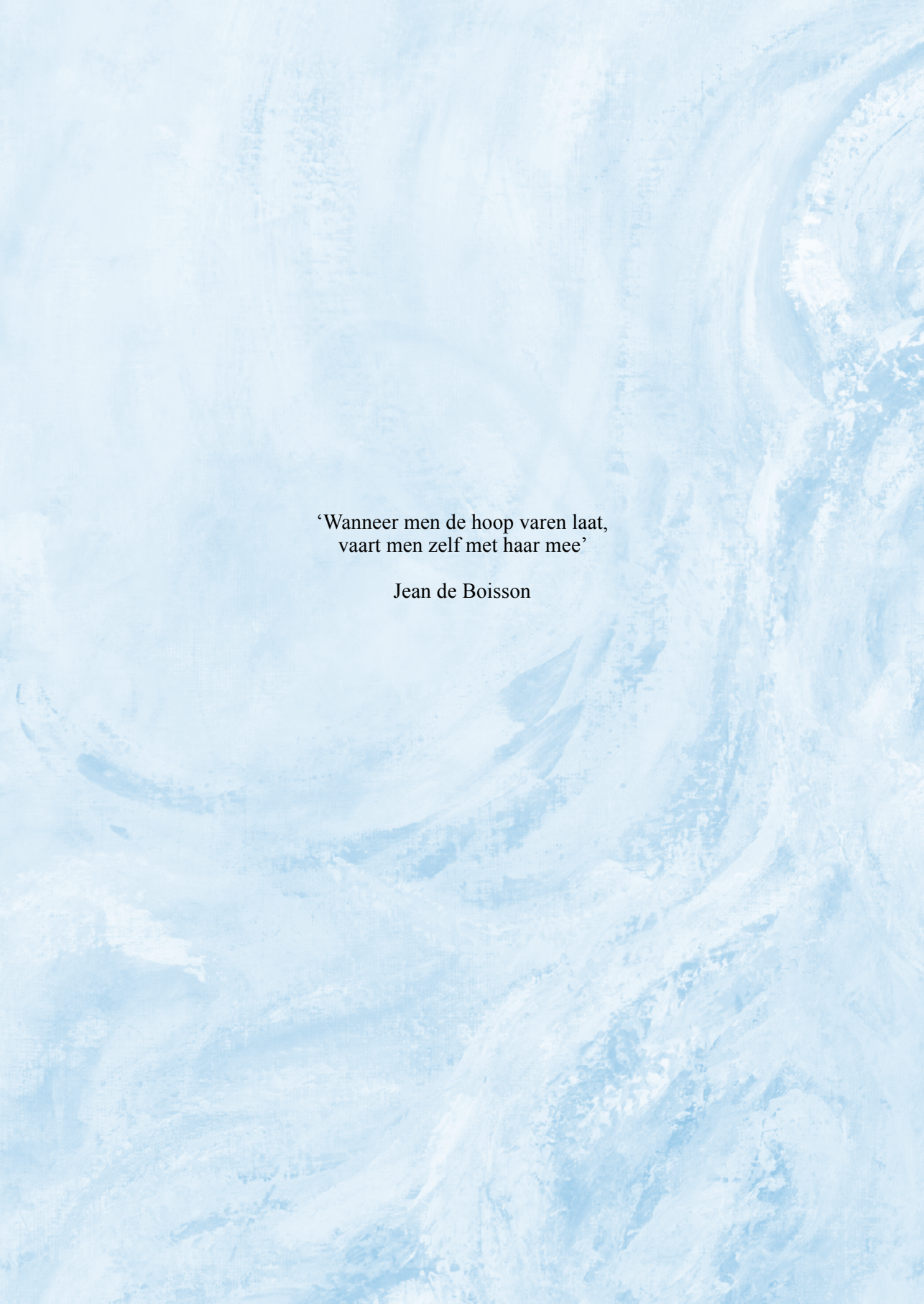
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‘Wanneer men de hoop varen laat,  
vaart men zelf met haar mee’

Jean de Boisson



# *Chapter 2*

Unbearable suffering of patients with a request for  
euthanasia or physician-assisted suicide:  
An integrative review

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Myrra J. Vernooij-Dassen  
Wim J. Dekkers  
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## Abstract

**Purpose** In the legal performance of the euthanasia procedure, unbearable suffering, one of the requirements of due care, is difficult to assess. Evaluation of the current knowledge of unbearable suffering is needed in the on-going debate about the conditions on which EAS can be approved.

**Methods** Using an integrative literature review, we evaluated publications with definitions of suffering in general or in end-of-life situations and with descriptions of suffering in the context of a request for EAS.

**Data synthesis** From the 1482 citations identified, we included 55 publications: 20 articles about definitions of suffering and 35 empirical studies on suffering. We found no definition of unbearable suffering in the context of a request for EAS. Qualitative patient-centred studies revealed the most motivations, and the most motivations named by only one of the three parties involved. The studies of relatives were limited, mainly quantitative and retrospective. We found no studies that brought together the views of the patients, relatives, and healthcare professionals.

**Conclusions** There is no generally accepted definition of ‘unbearable suffering’ in the context of a request for EAS. On the basis of the articles reviewed, we propose the following conceptual definition: ‘Unbearable suffering in the context of a request for EAS is a profoundly personal experience of an actual or perceived impending threat to the integrity or life of the person, which has a significant duration and a central place in the person’s mind’. Further patient-centred qualitative research into suffering is needed to clarify this definition.

## Background

There are just a few countries in the world where euthanasia or physician-assisted suicide (EAS) is legalized. The state of Oregon, USA, legalized physician-assisted suicide in 1994, where it represents 0.12% of the annual deaths.<sup>1</sup> Belgium legalized euthanasia in 2002, where it represents 0.3% of the annual deaths.<sup>2</sup> The Netherlands legalized EAS in April 2002, but Dutch law courts have permitted it since 1984, it represents 1.8% of the annual deaths.<sup>3</sup> In Switzerland, laws allowing physician- and non-physician-assisted suicide have been in place since 1941, which accounts for 0.36% of the annual deaths.<sup>3</sup> It is noteworthy that Australia’s Northern Territory legalized euthanasia temporally from 1996 to 1997.<sup>4</sup>

Unbearable suffering of patients is a major topic in granting a request for EAS. One of the requirements of due care in both the Dutch and the Belgian euthanasia acts

states that the attending physician must be convinced that the patient requesting EAS is in a situation of unbearable suffering.<sup>5,6</sup> Patients who request EAS present their perceived needs in terms of alleviating their suffering with assistance in dying. Compared to the other legal requirements, unbearable suffering is difficult to assess. Unbearable suffering has not yet been defined adequately and views on the concept are in a state of flux. Patients, physicians, members of the assessment committees, as well as the general public, politicians, philosophers, theologians, and ethicists constantly add their own perspectives to the discussion about unbearable suffering.

Understanding what makes suffering unbearable is crucial in a current request for EAS, and requires a physician who is able to understand the extent of suffering of patients in their specific situations.<sup>7,8</sup> This physician must be able to place the suffering in a conceptual framework.

Research has focused mainly on factors, motivations, and concerns associated with a request for EAS from the point of view of treating physicians and not on what makes suffering unbearable for patients. There is no definition of the “unbearable suffering” of patients who request EAS. The ethical and philosophical literature provides definitions of suffering of patients in general and in the end-of-life context.<sup>9-15</sup> The aim of this article is to provide a systematic overview of descriptions of unbearable suffering and current views on suffering of patients in the context of a request for EAS.

## Methods

### Definitions of euthanasia and physician-assisted suicide

Euthanasia (including physician-assisted suicide) is defined by the Dutch Government Commission on Euthanasia (1985) as the active and deliberate termination of a patient’s life by a physician on the patient’s request. In the case of physician-assisted suicide, the patient takes the lethal drugs him- or herself. The Belgian Euthanasia Act (2002) defines euthanasia as a deliberate termination of life on the request of the involved person by a physician.

Physician-assisted suicide under the Oregon Death with Dignity Act (1994) is defined as the prescription of a lethal dose of medication for a person with a terminal illness. Assisted suicide under article 115 of the Swiss Penal Code (1941) is defined as helping another to commit suicide, and it is not restricted to physicians.

### Search strategy

A method of concept analysis of the integrative review was used to guide the analysis.<sup>16</sup> This method includes both empirical and theoretical publications, which, in this case, describe suffering in the context of a request for EAS and give definitions of suffering. We searched the literature comprehensively, including PubMed, Embase, Cinahl, Web of Science, and Psych Info, which represent the

contemporary perspective on this topic. The search strategy was limited to adults and to English- and Dutch-language publications that were published between January 1, 1980 (the earliest available date) and June 30, 2007. In addition, we searched the Dutch and Flemish medical literature, using the library database of the Royal Dutch Medical Association, for information dated from January 1, 1990 (the earliest available date) to June 30, 2007. Various search terms were used to fully include the relevant literature: (euthanasia OR “end-of-life decision-making” OR “good death”) AND (suffering OR intractable pain OR intractable OR unbearable OR insufferable OR intolerable). The reference lists of the selected publications were checked for missing publications.

### **Inclusion and exclusion criteria**

Citations and abstracts were included when suffering and, euthanasia, physician-assisted suicide or hastened death was mentioned. Citations and abstracts were excluded when suffering was mentioned in combination with no actual wish for EAS, suicide, palliative or terminal sedation, non-resuscitation, refusal of food and fluids, passive euthanasia (shortening of life without the explicit consent of the patient), mental disability, impaired judgment, or dementia. Citations were also excluded if they mentioned only juridical, political, or ethical aspects of EAS or had not collected original data. Eventually, all publications in which a description of suffering of patients with an actual request for EAS or in which a definition of suffering of patients was given, were included.

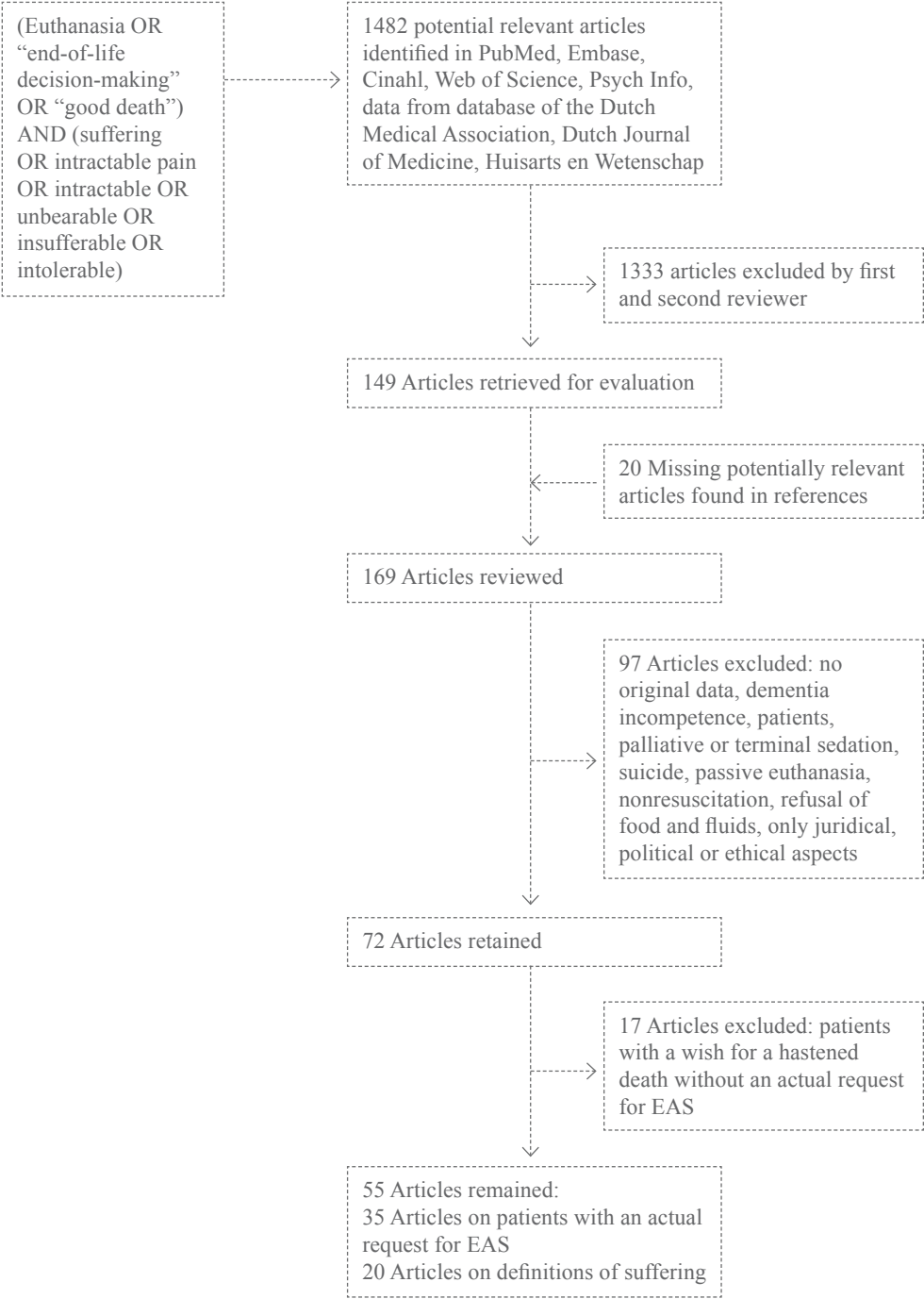
### **Data extraction and validation**

Two of the authors (MD and MV-D) independently reviewed the 1482 initially identified citations and abstracts, and they selected 149 relevant publications for possible inclusion in the review. The references of these publications revealed 20 missing potentially relevant articles. A first assessment of the full texts of these 169 publications excluded 97 articles that had no original data or did not refer to competent patients with a wish for a hastened death. Final assessment of the full texts of these 72 articles excluded 17 more articles because, although the referred patients had a wish for a hastened death, they had no actual request for EAS. Eventually 55 articles remained: 35 about patients with an actual request for EAS and 20 articles about definitions of suffering. The decision to include publications was reached by consensus.

The final sample for this integrative review included empirical and theoretical articles (Figure 1). The empirical articles included a wide variety of study designs: case studies, in-depth face-to-face interviews, semi-structured interviews, mailed interviews, instrument development designs, retrospective and prospective designs, and surveys and papers that reviewed case descriptions or death certificates. The same two authors independently reviewed the full text articles for motivations for EAS in the descriptions of suffering of patients, and for definitions of suffering.



Figure 1 Literature search and study selection process



EAS, euthanasia or physician-assisted suicide

The motivations were categorized according the characteristics of the reporting population: 1) patients reporting their own suffering, 2) healthcare professionals reporting suffering of patients, and 3) relatives reporting suffering of patients.

A data collection form was used to extract information about country or state, year in which the study was performed, legality of EAS, study design, setting, population characteristics, numbers of patients and motivations associated with and descriptions of suffering from the publications (Figure 2). All motivations, descriptions, and definitions were assessed in the light of our aim to contribute to the conceptualization of unbearable suffering in the context of a request for EAS. Finally, the extracted data were compared item by item and coded so that similar data could be categorized to facilitate distinction of patterns and variations and to extract themes.<sup>17,18</sup> Throughout the qualitative analysis, peer debriefing with the third and fourth (WD and CW) authors took place to stimulate reflection and control the interpretation process.

Figure 2 Data and collection form integrative review ‘unbearable suffering’

Sample: Patients/ Healthcare professionals/ Relatives	Country Setting Legality of PAS Underlying disease Number of patients	Research method Type of article	Definition or descriptions of ‘unbearable suffering’	Author(s) Year

## Results

### Included studies

Assessment of the 1482 publications retrieved in the first search, on the basis of the described data extraction and validation procedure, left 55 publications that fulfilled all criteria: 20 articles about definitions of suffering of patients and 35 empirical studies about suffering of patients with an actual request for EAS. Of these 35 empirical studies, 10 reported suffering of patients with an actual request for EAS directly, 16 reported the observations of healthcare professionals, 8 reported the observations of relatives and 1 reported motivations of physicians as well as family members. Table 1 shows the publications about theories and definitions of suffering of patients in general and in end-of-life situations presented in order of year of appearance with reference to the occupational field of the author. Tables 2, 3 and 4 present studies about the motivations associated with unbearable suffering in the context of a request for EAS as named by patients, healthcare professionals, and relatives that were extracted from the articles: unavoidable symptoms of the illness, fears about the circumstances of the approaching death, experienced loss of all that makes life worth living, confrontations with unsolvable problems in the communication with loved ones, and longings for autonomy and control. Table

2, 3 and 4 also give additional information about the country or state in which the studies took place, the legality of EAS, the setting, the underlying disease, the research method, and the numbers of patients involved.

**Table 1 Theories and definitions of suffering of patients in general and in end-of-life situations**

<b>Author, Year, Country</b>	<b>Professional field</b>	<b>Theories and definitions of suffering of patients</b>
Kahn et al, 1986, USA <sup>11</sup>	Nursing	An individual's experience of a threat to self and a meaning given to events such as pain or loss
Cassell, 1992, England <sup>9</sup>	Public health	The distress brought about by an actual or perceived impending threat to the integrity or continued existence of the whole person. It requires a sense of the future and of the past
Cherny, 1994, Israel <sup>10</sup>	Neurology	An adverse experience characterized by the perception of personal distress generated by adverse factors undermining the quality of life
Block et al, 1995, USA <sup>20</sup>	Psychiatry	Suffering contains four main areas: physical, psychological, social, and existential or spiritual suffering
Byock et al, 1996, USA <sup>26</sup>	Geriatrics	Personhood: dying and suffering are profoundly personal and cannot be reduced to a set of medical diagnoses. To comprehend the nature of suffering among the dying, it is essential to understand the person. This kind of suffering requires feeling the loss of meaning and purpose in life
Rodgers, 1997, USA <sup>13</sup>	Nursing	An individualized, subjective, and complex experience that involves the assignment of an intensively negative meaning to an event or a perceived threat
De Beijk, 1998, The Netherlands <sup>8</sup>	Internal nursing home	The factors associated with unbearable suffering can be listed under five subheadings nature of illness and prognosis, symptoms and problems associated with the treatment, loss of function, personal factors, and environmental factors
Emanuel, 1998, USA <sup>21</sup>	Ethics	Total suffering includes physical, mental, social, and spiritual suffering
van Hooft, 1998, Australia <sup>14</sup>	Ethics	Suffering refers to a state of psychological burden or oppression, typically marked by fear, dread, or anxiety
Alpers, 1999, USA <sup>22</sup>	Ethics	Dying patients can suffer from physical pain, other physical symptoms, spiritual and mental anguish caused by isolation, abandonment and a loss of control, refractory physical symptoms, indignity of living one's final days incapacitated, dying in a way that demeans one's values and poisons memories, undermining personal dignity and integrity
Chapman, 1999, USA <sup>60</sup>	Anesthesiology	Perceived damage to the integrity of the self, emerging when a discrepancy develops between one's expected self and one's experienced self. It is a psychological construct that represents a subjective state of identity
Kimsma, 2000, The Netherlands <sup>7</sup>	General practice Ethics	Suffering is an expression of the whole person affected by personal experiences and meaning, cultural values, and norms

Street, 2001, Australia <sup>25</sup>	Doctor who provides euthanasia	Loss of autonomy associated with dependence and shame connected with the loss of bodily functions
Edwards, 2003, England <sup>30</sup>	Philosophy	Intuitive concept of suffering: bound to the experience of threats felt contingently to the intactness of the self, with a significant duration and having a central place in the mental life of the person
Ashcroft, 2003, England <sup>23</sup>	Primary healthcare	Terminally ill in miserable pain and suffering with the prospect of decline and indignity, loss of control of bodily functions, control of mental competence, prospect of drawn-out death, the indignity of denial of autonomous control over passing
Dijkhuizen, 2005, The Netherlands <sup>29</sup>	Multidisciplinary area	Hopeless and unbearable suffering is not restricted to people with a classifiable physical or psychiatric illness, but may occur among people “suffering from life”
van Baarssen, 2006, The Netherlands <sup>19</sup>	Ethics	Physical (result of the illness) and emotional (result of loss, illness, aging, etc.) suffering can be distinguished within suffering. The second seems to have a greater impact
Chochinov, 2006, Canada <sup>27</sup>	Palliative care	Conceptual correlates of existential suffering toward the end of life include: hopelessness, burden to others, loss of sense of dignity, desire for death, loss of will to live
Hudson, 2006, Australia <sup>28</sup>	Research articles	Suffering is complex and multifactorial: psychological, existential, and social reasons seem to be more prominent
Murata, 2006, Japan <sup>12</sup>	Palliative care, professionals and peer reviewers	Definition of psycho-existential suffering: pain caused by extinction of the being and the meaning of the self. Caused by loss of relationships, loss of autonomy, and loss of temporality (future)
20 articles		

**Table 2 Motivations for euthanasia or physician-assisted suicide associated with unbearable suffering named by patients with an actual request**

Source and Location	Legality Setting Disease	Research method (Number of patients)	Motivations for EAS associated with unbearable suffering
Quill, 1994, USA <sup>31</sup>	Illegal Patients home Cancer	Case study (2)	Fears of a lingering, painful death out of control of mind and body, anguish, helplessness, indignity
van der Meer 1999, The Netherlands <sup>32</sup>	Illegal Patients home Multi-infarct dementia	Case study (1)	Losing one's self, demoralization, intellectual deterioration, loss of dignity
Lavery, 2001, Canada <sup>61</sup>	Illegal Setting unknown Aids/HIV	Qualitative study In-depth face-to-face interviews (32)	Experience or fear of disintegration or loss of community, perception of loss of self

Bascom 2002, USA <sup>62</sup>	Legal Patients home Amyotrophic lateral sclerosis	Case report (1)	Fear of pain, fear of drowning in one's own fluids, fear of burning in the legs, fear of being in a vegetative state for a long time, fear of a protracted, lingering death
De Burlet, 2003, The Netherlands <sup>63</sup>	Legal Nursery home Physical deterioration	Case report (1)	Being tired of life
Coyle, 2004, USA <sup>64</sup>	Illegal Setting unknown Cancer	Qualitative study, phenomenological inquiry (7)	Manifestation of the will to live, avoiding a difficult death, immediate situation being unendurable and requiring instant action, symptoms being incompatible with life (pain, shortness of breath), desire to control one's own death, attention drawn to uniqueness, altruism (intended to relieve the family of the burden of care and witnessing deterioration), manipulation to avoid abandonment, cry of despair
Mak, 2005, Hong Kong <sup>65</sup>	Illegal Palliative care Home Cancert	Qualitative study, unstructured in- depth interview (6)	Burden to the family, existential suffering, physical deterioration, poor quality of care, fear of future
McComby, 2005, France <sup>66</sup>	Illegal Palliative care unit Cancer, neurologic disease	Prospective survey, questionnaire (13)	Physical changes, loss of social roles, existential suffering, unrelieved symptoms (i.e. pain, anorexia, dyspnea, vomiting), family-related reasons (exhaustion, communication problems, conflicts, experiences with death or cancer, anticipated mourning, a promise made to the patient), depression, being a burden, fear of a difficult death, revenge, autonomy/dependence, adaptive disorders, evolution of the request
Pearlman, 2005, USA <sup>33</sup>	Illegal Home recruited through advocacy organizations Cancer, AIDS, neurologic disease, other	Qualitative research, longitudinal case study, semi-structured interview (35)	Illness-related experiences (i.e., feeling weak, fatigue, uncomfortable, pain and/or unacceptable side effects of pain medication, functional loss,), loss of sense of self, desire for control, fears about the future (i.e., quality of life and dying, negative experiences with dying)

Wilson, 2007, Canada <sup>67</sup>	Illegal Palliative care Cancer	Prospective semi-structured and open-end interviews (22)	<u>Motivations extracted from structured questions:</u> Being a burden, isolation, communication problems, financial problems, loss of resilience, loss of control, difficulty accepting, dissatisfaction with life, loss of dignity, weakness, general malaise, drowsiness, pain, breathlessness, nausea, anxiety, depression, hopelessness, loss of interest/pleasure, desire for death, suffering <u>Motivations, not mentioned above, extracted from answers on open-end questions:</u> terminal illness, loss of function, unwanted lingering, unhelpful treatments, pointlessness of continuing living, mere existence, old age, continuation of a difficult cancer experience, drain on healthcare resources, easier death/avoid suffering, retaining autonomy about dying, witnessed death of others
10 articles		120 patients	
EAS, euthanasia or physician-assisted suicide			

Table 3 Motivations for euthanasia or physician-assisted suicide associated with unbearable suffering of patients with an actual request named by healthcare professionals

Source Location	Legality Setting Profession	Research method (Number of patients)	Motivations for EAS associated with “unbearable suffering”
van der Wal, 1991, The Netherlands <sup>34</sup>	Illegal Patients home Physicians	Retrospective standardized questionnaire study (388)	General weakness or tiredness, dependence or being in need of help, loss of dignity, humiliation, pain
Leenen, 1994, The Netherlands <sup>68</sup>	Illegal Patients home General practitioners	Case history (1)	Mental suffering: inability to cope with life
Back, 1996, USA <sup>35</sup>	Illegal Family physicians, oncologists	Retrospective standardized questionnaire, last case, qualitative semi-structured interview (214)	Future loss of control, being a burden, dependence on others for personal care, loss of dignity, confinement to bed, severe depression or depressed mood, severe suffering, severe physical discomfort other than pain, severe pain, worries about medical costs
Groenewoudt, 1997, The Netherlands <sup>46</sup>	Illegal Setting unknown Psychiatrists	Retrospective standardized questionnaire, last case (200)	Absence of any hope of improvement, unbearable mental suffering, being a burden, pain or other physical suffering, loss of dignity

Chin, 1997, USA	Legal Divers settings Physicians	Retrospective physicians' report, death certificates, open-end interviews (21)	Loss of autonomy, loss of control of bodily functions
Haverkate, 2000, The Netherlands <sup>47</sup>	Illegal Diverse settings Physicians	Retrospective structured interview, last case (282)	Loss of dignity, unbearable or hopeless suffering, weariness of life, fear of becoming a burden to the family
Sullivan, 2000, USA <sup>37</sup>	Legal Diverse settings Physicians	Review of death certificates, retrospective semi- structured interview (27)	Loss of autonomy, inability to participate in activities that make life enjoyable, loss of control of bodily functions
Ganzini, 2002, USA <sup>69</sup>	Legal Hospice Nurses, social workers	Retrospective mailed semi-structured questionnaire, last case (120)	Desire to control circumstances of death, readiness for death, desire to die at home, continued existence, loss of independence or fear thereof, poor quality of life or fear thereof, loss of dignity or fear thereof, pain or fear of worsening pain, inability to care for oneself or fear thereof, perception of oneself as a burden to others or fear of becoming a burden, inability to engage in pleasurable activities, life tasks complete, fatigue or fear of worsening fatigue, dyspnea or fear of worsening dyspnea, lack of social support, loss of or fear of losing bowel or bladder function, confusion or fear thereof, experience of witnessing bad deaths, perception of oneself as a financial drain on others or fear of becoming a financial drain, depression or other psychiatric disorder, nausea or fear of worsening nausea, lack of social support
Virik, 2002, Australia <sup>45</sup>	Illegal Palliative care unit Palliative team	Retrospective standardized instrument (6)	Issues of burden and dependency: lack of autonomy and control, lack of social support, sense of hopelessness, sense of social isolation, depression Physical symptoms: pain, shortness of breath, fatigue, nausea
Meier, 2003, USA <sup>48</sup>	Legal Diverse settings Physicians	Retrospective self report semi-structured questionnaire, last case (415)	Heavy burden of physical symptoms, described as being depressed

Marquet, 2003, The Netherlands <sup>39</sup>	Legal Patients home Physicians	Retrospective standardized questionnaire (915)	Fear of pain, deterioration, hopelessness, dyspnea
Georges, 2005, The Netherlands <sup>40</sup>	Legal Setting unknown Physicians	Prospective monthly structured questionnaire, retrospective semi- structured interview, last case (106)	Feeling extremely unwell, severe pain, nausea, vomiting, coughing, high average of severe physical symptoms. Nonphysical symptoms: relationships to others, concerns about loss of autonomy, loss of bodily functions, concerns about future distress, becoming a burden to others, feeling meaningless, dependency, loss of dignity
Jansen-van der Weide, 2005, The Netherlands <sup>44</sup>	Legal Patients home Physicians	Retrospective standardized questionnaire, Last case (1537)	Pointless suffering, loss of dignity, weakness, pain, fear of suffocation, disability, immobility, being a burden, tired of living, vomiting, feeling depressed
Rurup, 2005, The Netherlands <sup>42</sup>	Legal Patients home Physicians	Retrospective standardized questionnaire, last case (139)	“Tired of living”: feeling bad, feeling tired, not active, high prevalence of physical symptoms without classifiable severe disease
Rurup, 2005, The Netherlands <sup>43</sup>	Legal Setting unknown Physicians	Retrospective interview study, last case (29)	Reasons for a request in the absence of a severe disease: through with life, physical decline, tired of life, no purpose in life, melancholy, depression, loneliness, dependence, suffering from life, deterioration, loss of dignity, loss of status, not wanting to be a burden on the family any more, pain, cognitive decline, death of a relative, unable to live independently
Georges, 2006, The Netherlands <sup>41</sup>	Legal Setting unknown Physicians	Prospective structured interview, monthly standardized questionnaire (16)	Dignity, physical suffering mixed with concerns and psychological problems
Oregon Department of Human Services, 2007, USA <sup>1</sup>	Legal Diverse settings Physicians	Retrospective self standardized questionnaire (292)	Losing autonomy, less able to engage in activities making life enjoyable, loss of dignity, losing control of bodily functions, being a burden, inadequate pain control or concern about it, financial implications of treatment
17 articles		4698	

EAS, euthanasia or physician-assisted suicide



**Table 4 Motivations for euthanasia or physician-assisted suicide associated with unbearable suffering of patients with an actual request named by relatives**

<b>Source Location</b>	<b>Legality Relation Disease</b>	<b>Research method (Number of patients)</b>	<b>Motivations for EAS associated with “unbearable suffering”</b>
Seale, 1994, England <sup>52</sup>	Illegal Bereaved relatives	Retrospective (x)	Dependence, pain (mainly related to patients with cancer)
Zwart, 1997, The Netherlands <sup>55</sup>	Illegal: sustained under special conditions Granddaughter Cancer	Case study (1)	Loss of dignity, fatigue
Poenisch, 1998, USA <sup>51</sup>	Illegal Daughter Amyotrophic lateral sclerosis	Case study (1)	Not being able to communicate, being dependent, fear of choking to death, tired of struggling against the disease
Sullivan, 2000, USA <sup>37</sup>	Legal Family members	Reviewing death certificates, semi-structured interview (19)	Loss of control of bodily function, loss of autonomy, inability to participate in activities that make life enjoyable concern about being a burden
Ganzini, 2002, USA <sup>38</sup>	Legal Caregivers Amyotrophic lateral sclerosis	Standardized quantitative instrument (50)	Distress at being a burden, insomnia, discomfort other than pain, hopelessness, interest in assisted suicide earlier in the disease
Morita, 2004, Japan <sup>50</sup>	Illegal Family Palliative care	Self report standardized questionnaire (29)	Burden on others, meaninglessness, inability to pursue pleasurable activities, general malaise, pain, dyspnea, concerns about future distress, wish to control time of death
Tolle, 2004, USA <sup>54</sup>	Legal Family caregivers	Self report standardized questionnaire (25)	More symptoms with pain and sadness most associated with an interest in physician-assisted suicide. Those taking a lethal injection did not commonly report pain
Starks, 2005, USA <sup>53</sup>	Illegal and legal Family Home care hospices	Retrospective and prospective semi-structured interviews (35)	Exercise control over dying process especially when perceiving a future of intolerable suffering or no possibility of restoring the sense of personal integrity. Experiencing an acute event or treatment. Inability to cope with being weak, vulnerable, and dying. The remaining course of illness. Willingness to stay engaged with struggle. Availability of others to help with hastening death

Georges, 2007, The Netherlands <sup>49</sup>	Legal Relatives	Retrospective cross-sectional structured interview (87)	Hopeless suffering, loss of dignity, no prospect of recovery
9 articles		247 patients + x	

X means that no exact number was given  
EAS, euthanasia or physician-assisted suicide

**Theories and definitions (Table 1)**

Although every study did refer to suffering or “unbearable suffering” in the end-of-life context, we found no generally accepted definition, which confirms Cassell’s<sup>15</sup> earlier conclusion. Kahn<sup>11</sup> defines suffering as “an individual’s experience of threat to self and a meaning given to events such as pain or loss”. Cassell<sup>9</sup> defines suffering from observations of patients as “the distress brought about by an actual or perceived impending threat to the integrity or continued existence of the whole person, it requires a sense of the future and of the past”. This stresses the importance of the individual patient’s perceptions. Additional clarifications, but no new definitions, were found in the remaining articles. Theories based on observations of terminally ill patients who requested EAS named four themes of suffering: physical, psychological, existential or spiritual, and social.<sup>19-21</sup> It was emphasized that suffering in this specific context is generated by factors undermining the quality of life<sup>22-25</sup> and by the perceived loss of meaning and purpose in life.<sup>12;26-29</sup> In many of the articles, the influence of the profoundly personal perception of the suffering is underlined. Edwards adds that unbearable suffering has a significant duration and a central place in the mental life of the person.<sup>30</sup>

**Motivations named by patients (Table 2)**

The 10 patient-centered studies, all with a qualitative design, included 120 mostly incurably ill patients, and were performed in countries where EAS was or was not legal. A closer look at the patients’ motivations, once they had been extracted from their very personal stories, showed that patients express their unbearable and unrelieved suffering in terms of pain, weakness, functional impairment, dependency, being a burden, hopelessness, indignity, intellectual deterioration, perception of loss of oneself, loss of autonomy, and being tired of life. Those are in themselves inevitable effects of illness and even the best palliative care cannot provide a lasting solution. The point where suffering becomes unbearable is a very individual perception that is closely related to the personality, the life history, social factors, and existential motivations. Irreversible disintegration and humiliation of the person appeared to be the start of openly exploring the phenomenology of death. The circumstances of their illness brought all the patients to the point where they would rather die than continue to live under the conditions imposed by their illness.<sup>31</sup> The circumstances that brought these patients to ask for EAS appeared to be very diverse. This was illustrated, for example, in the difficult process of a

67-year-old patient who was a former adjunct director and an erudite man, and who suffered unbearably because he did not recognize himself in the impulsive and compulsive personality he became after many brain infarctions.<sup>32</sup> Another example is the 62-year-old woman, organized, energetic, and athletic, involved in community activities, a grandmother who could face the painful complications brought on by metastatic ovarian cancer, but could not bear the physical frailty, the prospect of hospitalization, and the loss of control that were her worst fears come true.<sup>33</sup>

### **Motivations named by healthcare professionals (Table 3)**

The 17 studies centered on healthcare professionals combined quantitative and qualitative designs and involved 4695 patients. These studies were predominantly from countries where EAS was legal. In the first large study, by van der Wal et al.<sup>34</sup>, the family doctors who had carried out EAS stated that most patients suffered physically as well as emotionally. “General weakness or tiredness” was the aspect most often referred to. “Dependence or being in need of help”, “loss of dignity, humiliation” and “pain”, were frequently named. These findings were confirmed in later studies<sup>1,35-44</sup> that report that most of the common concerns of patients at the time they request EAS are not physical, and they are based on many factors.<sup>45</sup> This was illustrated in a report of a consulting physician in an EAS procedure of a 92-year-old woman who had had surgery for a colon carcinoma when she was 82. She had had untreatable abdominal pains ever since the surgery 10 years previously, fell frequently due to balance problems, and was unable to read, write, or watch television due to macular degeneration. All her relatives and friends of her own age had died, and she had become increasingly lonely.<sup>43</sup> Studies in the Netherlands have made it obvious that patients whose requests for EAS had been denied had more mental health problems than patients whose requests had been granted.<sup>46</sup> A study among Dutch psychiatrists revealed that they were more likely to give assistance in dying if the patient had a serious physical illness in a terminal phase.<sup>47</sup> A large American survey among physicians involved in the care of seriously ill patients shows that patients were more likely to receive assistance in dying when they were seriously ill with little time to live and with a larger burden of physical symptoms.<sup>48</sup>

### **Motivations named by relatives (Table 4)**

Seven of the nine relative-centered studies had a quantitative, retrospective design, two were case studies. These studies included 247 + x patients in total, and they were carried out in countries where EAS was or was not legal. The findings point to the importance of dependency, the emotional impact of loss of dignity and personal integrity, tiredness, and the fears of the circumstances of the unavoidable death rather than pain.<sup>37,44;49-55</sup> This was profoundly described by the daughter of a patient with amyotrophic lateral sclerosis: “She wanted to be able to communicate when she was hungry or full, and when she her airways needed to be sucked out.

She didn't want to choke to death while waiting for her caregiver to unblock her airway. She wanted to be able to write to her legislators. She wanted to be able to use the toilet herself. The disease progressed like a cocoon being spun around her. The outside world was slowly being taken away".<sup>51</sup>

Table 5 Motivations for euthanasia or physician-assisted suicide associated with unbearable suffering of patients with an actual request named by patients, healthcare professionals, and relatives

<b>Medical: physical</b>			
<b>Motivations for EAS</b>	<b>Patients</b>	<b>Professionals</b>	<b>Relatives</b>
Anorexia*	X*	-	-
Breathlessness	X	X	-
Confinement to bed*	-	X*	-
Coughing*	-	X*	-
Dependence	-	X	X
Discomfort other than pain	X	X	X
Dyspnea	X	-	X
Drowsiness*	X*	-	-
Fatigue	X	X	X
General malaise	X	X	X
Immediate situation being unendurable, requiring instant action	X*	-	-
Insomnia*	-	-	X*
Nausea	X	X	-
Pain	X	X	X
Physical deterioration	X	X	-
Physical suffering mixed with concerns and psychological problems*	-	X*	-
Side effects of pain medication*	X*	-	-
Vomiting	X	X	-
Weakness	X	X	-
<b>Medical: mental disorder</b>			
Adaptive disorder*	X*	-	-
Anxiety disorder*	X*	-	-
Depression	X	X	-
Intellectual deterioration*	-	X*	-
Organic mental disorder*	-	X*	-
Personality disorder*	-	X*	-
Substance abuse disorder*	-	X*	-
Sum of motivations/ *	17/6*	18/7*	7/1*

<b>Psychological</b>			
<b>Motivations for EAS</b>	<b>Patients</b>	<b>Professionals</b>	<b>Relatives</b>
Anguish*	X*	-	-
Avoiding a difficult death	X	-	X
Evolution of the request*	X*	-	-
Desire to control own death	X	X	X
Difficulty accepting	X*	-	-

Fear of:			
Becoming a burden to the family*	-	X*	-
Burning in his legs*	X*	-	-
Deterioration*	-	X*	-
Disintegration*	X*	-	-
Drowning in one's own fluids*	X*	-	-
Dyspnea*	-	X*	-
Future loss of control	-	X	X
Future quality of life*	X*	-	-
Hopelessness*	-	X*	-
Lengthy vegetative state*	X*	-	-
Lingering, painful death out of control of mind and body*	X*	-	-
Loss of community*	X*	-	-
Negative experiences with dying*	X*	-	-
Pain	X	X	-
Suffocation	-	X	X
Uncontrollable symptoms*	-	X*	-
Feeling lonely*	-	-	X*
Having a terminal illness*	X*	-	-
Having no energy left to fight the illness*	-	-	X*
Manifestation of the will to live*	X*	-	-
Sadness*	-	-	X*
Sum of motivations/*	16/13*	9/5*	7/3*

<b>Social</b>			
<b>Motivations for EAS</b>	<b>Patients</b>	<b>Professionals</b>	<b>Relatives</b>
Altruism (intended to relieve the family of the burden of care and witnessing deterioration)*	X*	-	-
Being a burden	X	X	X
Communication problems	X	-	X
Death of a relative*	-	X*	-
Drain on healthcare resources*	X*	-	-
Draw attention to uniqueness*	X*	-	-
Encumber loved ones with painful memory*	-	X*	-
Family-related reasons (exhaustion, communication problems, conflicts, experiences with death or cancer, anticipated mourning, a promise made to the patient)*	X*	-	-
Financial problems	X	X	-
Isolation	X	X	-
Manipulation to avoid abandonment*	X*	-	-
Poor quality of care*	X*	-	-
Slow separation	-	X*	-
Sum of motivations/*	10/6*	6/3*	2/0*

<b>Existential</b>			
<b>Motivations for EAS</b>	<b>Patients</b>	<b>Profes-sionals</b>	<b>Relatives</b>
Absence of any hope of improvement	-	X	X
Being tired of life	X	X	-
Continuation difficult cancer experience*	X*	-	-
Desire for death*	X*	-	-
Demoralization	X	X	X
Dissatisfaction with life*	X*	-	-
Experience of disintegration or loss of community*	X*	-	-
Helplessness*	X*	-	-
Hopelessness	X	X	X
Inability to participate in activities that make life enjoyable	-	X	X
Loss of:			
Autonomy	X	X	-
Control	X	X	-
Dignity	X	X	X
Function*	X*	-	-
Independence*	-	X*	-
Interest and pleasure*	X*	-	-
Occupational roles*	-	X*	-
Resilience*	X*	-	-
Sense of self*	X*	-	-
Sexual desire*	-	X*	-
Social roles	X	X	-
Status*	-	X*	-
Mere existence*	X*	-	-
No purpose in life	-	X	X
Old Age*	X*	-	-
Pointlessness continuing living*	X*	-	-
Unhelpful treatments*	X*	-	-
Sum of motivations/ *	20/13*	14/4*	6/0*

\*The motivation is named exclusively by one of the three groups  
EAS, euthanasia or physician-assisted suicide

### **Summarization of motivations for EAS associated with unbearable suffering (Table 5)**

We found 90 motivations associated with unbearable suffering in the context of a request for EAS. The patient-centered studies revealed the most motivations (63), of which 38 were not reported by professionals and relatives. The studies centered on healthcare professionals reported 47 motivations, with 19 named only in this group. The relative-centered studies reported 22 motivations, four of them not named by professionals and patients. Further analyses of the motivations with the constant comparison technique revealed four themes within all three populations, namely: a medical (in which there were a physical dimension and

a mental dimension), a psychological, an existential (or spiritual), and a social theme. Summarizing the motivations of the three populations studied showed that the medical ( $n = 26$ ), the psychological ( $n = 26$ ) and the existential theme ( $n = 27$ ) contributed almost equal numbers of motivations to unbearable suffering in the context of a request for EAS. The social theme ( $n = 13$ ) was named far more less. Relatives contributed few motivations for all four of the themes. Patients contributed the most motivations for all but the medical theme. Medical motivations were equally common among patients and professionals. Professionals named the mental diagnoses of personality disorder and substance abuse disorder as motivating requests for EAS, while the patients named adaptive and anxiety disorders. Within the medical theme, “discomfort other than pain, fatigue, general malaise and pain” were the only motivations common to patients, professionals, and relatives. Existential motivations were particularly named by patients ( $n = 20$ ), professionals contributed 14 motivations. More than half of the existential motivations were about loss, like “loss of independence, of occupational roles, of sexual desire and of status”. Within the existential theme only “demoralization, hopelessness, and loss of dignity” were shared among patients, professionals, and relatives. Most psychological motivations were about fear ( $n = 16$ ), like “fear of becoming a burden, fear of a painful death, fear of dyspnea and fear of suffocation”. Relatives named “feeling lonely, having no energy left to fight the illness and sadness”. The “desire to control one’s own death” was the only psychological motivation shared among patients, professionals, and relatives. Within the social theme, patients named “altruism, communication problems, drawing attention to one’s uniqueness, family-related reasons, and poor quality of care”. “Being a burden” was named by patients, as well as by professionals and relatives.

## Discussion

This review analyzes the current definitions of “suffering” and the motivations for EAS associated with “unbearable suffering” as given by patients, healthcare professionals, and relatives. The a priori inclusion criteria of this review have restricted inclusion to articles that refer to suffering in the context of an actual request for EAS. No agreed-upon definition of unbearable suffering in end-of-life situations materialized. The analysis has revealed that suffering has medical, psychological, existential, and social dimensions, and we found many different motivations.

It is noteworthy that patients, healthcare professionals, and relatives presented their own sets of motivations, with little overlap. The review has also made it clear that there are no empirical articles in which motivations given by patients and healthcare professionals are compared, and that there is a lack of research that gives insight into the views of relatives about the suffering of patients who request EAS. Nevertheless, the empirical articles provided us with a wealth of motivations



for EAS associated with suffering of patients who made an actual request.

The four dimensions we found are compatible with the four domains frequently referred to in theoretical articles, as well as in the Saunders' model of "total pain" in which physical, mental, social and spiritual factors are considered to contribute to suffering in terminal disease.<sup>56</sup> In the context of suffering of patients who request EAS, it seems convenient to combine the physical motivations and mental disorders in a medical theme, the domain of the medical professionals. With regard to elements that address meaning, both the words "spiritual" and "existential" are used. In relation to suffering in the context of a request for EAS, it seems appropriate to use the term "existential" if the continuation of the existence of the patient is threatened.

A closer look at the motivations makes it obvious that the large variety of motivations contributes to the complexity of suffering in the context of a request for EAS. The wealth of motivations illustrates that unbearable suffering is the result of a complex interaction of symptoms of the disease, personality and personal experiences, the existential background, and the social situation. Comparison of the motivations given by patients, professionals, and relatives identified no specific trends, but did highlight many motivations named by only one group and few shared motivations.

These findings may be the result of differences in views on suffering among the three populations under study. They may also be influenced by differences in research methods and settings among the three populations. It is noteworthy that many of the EAS monitoring studies in the Netherlands and Oregon, where ascertaining the severity of the suffering is an essential part of the assessment procedure, included only the opinions of professionals and relatives, and that there are remarkable differences in the motivations of patients on the one hand and professionals and relatives on the other hand. Knowledge of the patients' perspectives on unbearable suffering may have policy implications in these countries. Bearing in mind the possible differences in views on suffering between patients and physicians, the question that emerges is: how do treating physicians come to an understanding of the severity of suffering in individual cases in the absence of an agreed-upon definition?

There are limitations that should be considered in interpreting the results of the empirical publications that we have reviewed. There are few empirical studies about patients, who have actually requested EAS, and they are restricted to a few countries, and the legality status may influence the motivations named. The studies centered on healthcare professionals are mainly restricted to countries where EAS is legal: for this reason motivations considered illegal may be missing. There are the difficulties that the studies vary in population demographics and research

methods, no restrictive criteria related to study quality were used, and the same patients are entered more than once. Therefore, no conclusions can be drawn from the frequency with which the motivations are named. Differences in study methods among the three populations influence and limit variations and therefore comparability of the motivations. Although a broad variety of motivations is found to be associated with actual requests for EAS, some of these motivations are poorly defined, which makes comparison and interpretation difficult. Most studies include only cancer patients, and their medical life histories may differ from those of patients with chronic, debilitating, or mental disorders. The wealth of motivations and the differences among patients, healthcare professionals, and relatives underlines the fact that unbearable suffering is a profoundly personal and subjective experience.

A conceptual definition of unbearable suffering applicable in the context of a request for EAS must do justice to the uniqueness of the individual who makes the request. On the basis of the results of the integrative review, we conclude that this uniqueness is best expressed in Cassell's earlier description. This description underlines the fact that suffering involves the person as a whole, which is compatible with the four themes we found in the data analysis. We propose the following conceptual definition: "Unbearable suffering in the context of a request for EAS is a profoundly personal experience of an actual or perceived impending threat to the integrity or life of the person, which has a significant duration and a central place in the person's mind". This definition emphasizes the potential dilemmas that healthcare professionals face when dealing with a request for EAS, and it can help professionals respond. This definition also underlines the fact that healthcare professionals should explore the four themes of suffering with individual patients from an early stage of their illness. This should be done not only to diagnose and treat it before it becomes unbearable, but also to be able to understand and assess unbearable suffering when the illness leads to a request for EAS. These professionals are required to have communicative skills, empathy, knowledge of medical, psychological, existential, and social aspects of suffering in end-of-life contexts, as well as the capacity to reflect on the patient's own subjective perceptions of suffering.

Our review has made obvious that patient-centered studies, with a qualitative in-depth interview design, bring to light the most motivations and the most motivations named by only one of the three groups involved. This is in line with earlier recommendations<sup>9-11;57-59</sup> with regard to the benefits of qualitative research strategies for understanding end-of-life situations. Bearing in mind the importance of "unbearable suffering" in the decision-making process for a request for EAS, it is obvious that further research into suffering in the context of requests for EAS is necessary. Such research should focus on the patients, relatives, and professionals involved in end-of-life situations. Qualitative research using in-depth interviewing

techniques is best suited to uncovering the hidden dimensions of the patients' motivations for EAS as well as the professionals' and relatives' views on suffering in individual cases. We think it is a challenge to combine such new qualitative data with earlier quantitative work to find new directions for future research aimed at improving decision-making in end-of-life situations.

## **Conclusion**

The aim of this integrative review was to study unbearable suffering in the context of requests for EAS. The review makes it clear that there is no generally accepted definition of "unbearable suffering" in the context of a request for EAS. It also shows that the term "unbearable suffering" has medical, psychological, existential, and social dimensions, and that there are many different motivations. Patients, healthcare professionals, and relatives appear to present their own sets of motivations. On the basis of our review, we propose a conceptual definition. The wide variety of motivations and the variability of motivations among patients, healthcare professionals, and relatives make it clear that qualitative research is needed to gain more insight into the unbearable suffering of patients who request EAS. Such a study would preferably address the patient, the professionals, and the relatives involved in the request.

## **Acknowledgments**

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‘Claustrofobie voor mijn bestaan  
De woorden vloeien vanzelf  
suïcide gedachten  
maar ik ben opgesloten  
in mijn dwangbuis van ziekte en angst  
zo ondoordringbaar  
dat niemand me kan horen  
schreeuwen’

Manja Croiset (P 20)



# *Chapter 3*

“Unbearable suffering”: A qualitative study on the perspectives of patients who request assistance in dying

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## Abstract

**Background** One of the objectives of medicine is to relieve patients' suffering. As a consequence, it is important to understand patients' perspectives of suffering and their ability to cope. However, there is poor insight into what determines their suffering and their ability to bear it.

**Purpose** To explore the constituent elements of suffering of patients who explicitly request euthanasia or physician-assisted suicide and to better understand unbearable suffering from the patients' perspective.

**Patients and methods** A qualitative study using in depth face-to-face interviews was conducted with 31 patients who had requested physician-assisted suicide. The grounded theory approach was used to analyse the data.

**Results** Medical, psycho-emotional, socio-environmental and existential themes contributed to suffering. Especially fatigue, pain, decline, negative feelings, loss of self, fear of future suffering, dependency, loss of autonomy, being worn out, being a burden, loneliness, loss of all that makes life worth living, hopelessness, pointlessness and being tired of living were constituent elements of unbearable suffering. Only patients with a psychiatric (co) diagnosis suffered unbearably all the time.

**Conclusions** Unbearable suffering is the outcome of an intensive process that originates in the symptoms of illness and/or ageing. According to patients, hopelessness is an essential element of unbearable suffering. Medical and social elements may cause suffering, but especially when accompanied by psycho-emotional and existential problems suffering will become 'unbearable'. Personality characteristics and biographical aspects greatly influence the burden of suffering. Unbearable suffering can only be understood in the continuum of the patients' perspectives of the past, the present and expectations of the future.

## Introduction

The main objectives of medicine are to relieve patients' suffering and cure their illness.<sup>1</sup> Once patients can no longer be cured, palliative care is employed to improve the quality of life by prevention and relief of suffering.<sup>2</sup> The availability of palliative care has increased in the past decades.<sup>3,4</sup> Nevertheless 1 in 10 palliative care patients have asked, at some point, a specific question about assistance in dying to alleviate suffering.<sup>5-7</sup> In states and countries where euthanasia or physician assisted suicide (EAS) has been legalised Oregon, Washington State, Montana,

Switzerland, Belgium, Luxembourg and the Netherlands unbearable suffering is a major consideration in the professional assessment of a request for EAS.<sup>6-10</sup> In an integrative literature review we established that unbearable suffering in the context of a request for EAS has a medical, a psychological, a social and an existential dimension.<sup>11</sup> It also made it obvious that despite its essential place in end-of-life decision-making, there is no generally accepted definition of ‘unbearable suffering’ and there is a lack of knowledge of patients’ perceptions of ‘unbearable suffering’.<sup>11</sup> In the Netherlands, patients who explicitly request EAS are expected to describe their situation in terms of a lack of hope and an inability to cope with their suffering. This provides a unique opportunity to study unbearable suffering from the patient’s perspective. Qualitative research using in-depth interview techniques is best suited to uncover unbearable suffering from the patients’ perspectives. Understanding ‘suffering’ and knowledge of its constituent elements provides a tool that might contribute to an early detection and a proactive approach to prevent suffering becoming unbearable. We conducted a study to explore what patients who had explicitly requested EAS considered ‘suffering’ to entail and what made their suffering ‘unbearable’.

## **Methods**

### **Study design**

We used a design of qualitative, in-depth, face-to-face interviews.<sup>12,13</sup> Purposeful sampling was used to ensure diversity in diagnosis.

### **Recruitment and patient selection**

With the assistance of the Support and Consultation on Euthanasia in the Netherlands (SCEN) network, we recruited patients who had explicitly requested EAS. We also approached a hospice, a hospital and a nursing home and placed a notice in the journal *Right to die-NL*. To ensure diversity in the sampling of perceived suffering, we included both patients whose EAS requests had been granted and denied. The treating physician was asked to inform the patient about the study. The interviewer contacted the patient by telephone and written information was sent by mail. Patients who reacted to the notice could directly contact the interviewer by phone. All patients signed an informed consent form.

### **Interviews**

The interviews took place at the patients’ residences and lasted 30-120 min. Patients were interviewed alone to ensure that the caregiver’s presence did not influence the information they gave. We developed an interview guide (Box 1) on the basis of the research question and a literature review.<sup>11</sup> Each interview started with a question about the development of the request. Subsequently constituent elements of suffering were explored. All patients were asked about their ability to enjoy things. Finally each patient was asked what made suffering unbearable. The

interviewer (MK), a family physician and SCEN specialist, closely followed the interview line brought forward by the patient.<sup>14</sup> The interviews were audio-taped and transcribed verbatim. Demographics were collected before the interviews and the medical records and SCEN reports were retrieved afterwards.

#### Box 1 Interview guide

- How did your request for euthanasia or physician-assisted suicide develop?
- What made your request topical?
- What is your suffering made up of?
- What makes your suffering unbearable?

### Definitions

In accordance with the Dutch law, euthanasia was defined as the termination of life on the explicit request of the patient by a physician with the intention to end hopeless and unbearable suffering. Physician-assisted suicide was defined as assisting in the suicide of a patient by a physician. A request for EAS is called 'explicit' when the patient has specifically asked the physician to (help) end the patient's life.

### Qualitative data analysis

We used the constant comparative method to analyse the data.<sup>15</sup> This method is part of the grounded theory approach in which concepts emerge as theory is formed. We used ATLAS.ti version 5.5 software to process the data. Analysis started as soon as the first data were collected and continued with each additional interview. The first step in the analysis was data reduction; two researchers (MD and a psychologist LR) coded the transcript independently to minimise subjectivity. Coding is the interpretive process in which we give conceptual labels to the data. The purpose is to attain new insights by breaking through standard ways of thinking about phenomena reflected in the data.<sup>15</sup> The sequence was as follows: we used codes that were closely related to the text fragments. After five interviews, we compared the analysts' codes and three researchers (MD, LR and MV) discussed them until they reached consensus. Then a new coding scheme was developed for further use. New codes could be added. When no more new codes about suffering appeared, we were satisfied that saturation had been reached. We grouped codes referring to the same phenomenon in categories and categories in themes. MD analysed all transcripts again to come to an understanding of how the different elements of suffering contributed in individual cases to unbearable suffering. Finally, a grounded theory approach was used to derive hypotheses about unbearable suffering from the data. Five researchers reached consensus about the codes, categories and themes in peer-group discussion. This group included two family doctors (CW and MD), one of whom has experience with EAS (MD), a sociologist experienced in qualitative end-of-life research (MV), an ethicist (WD) and a palliative care specialist (KV). They used an iterative procedure and re-reading to facilitate the discussion.



## Results

Between April 2008 and July 2009 45 patients were prepared for interviewing. Twelve were excluded after interviewing because they had not made an explicit request. Two patients died before their interviews could take place. Altogether, 31 patients were included in the study. When data from the last seven interviews were entered, no new codes emerged and we concluded that saturation had been reached.

### Patient characteristics

The participants varied in gender, age, marital status, educational level and residence. They came from rural and urban areas all over the Netherlands. Except those with a psychiatric diagnosis, these patients showed a high degree of self-realisation in social, occupational and economic status. Five patients considered themselves religious. The requests of 11 patients were not granted. In eight cases, this refusal was directly related to the absence of a physical diagnosis (four patients had psychiatric diseases and four patients were tired of living). Two refusals were related to the institutional policies of the places of residence. These patients died as a result of non-treatment of pneumonia and palliative sedation. The request of one patient with cancer was refused because of the coexistence of a depression. He refused treatment and stopped eating and drinking. The request of a second patient with cancer was postponed by successful treatment of her depression. According to the medical records and the reports of SCEN consultants all patients were clinically assessed on depression. The life expectancy of the patients with cancer, at the moment EAS was performed, varied from 2 to 120 days with a mean of 34 days (Table 1).

### The patients' perspectives on suffering

The patients described suffering in a multiplicity of very individual ways (Table 2). The coding of their statements resulted in 21 categories from which, in accordance with our literature review<sup>11</sup> four themes emerged: medical, psycho-emotional, socio-environmental and existential (Table 3).

### The medical context

Suffering always originated in symptoms of illness or ageing. Within the medical theme five categories could be distinguished: physical, cognitive and psychiatric symptoms, side effects of medical treatment and decline. The physical symptoms varied greatly, depending on the specific course of the illness or ageing. Of the physical symptoms general symptoms such as fatigue, pain, feeling miserable increased suffering more than tractus related symptoms. Decline was often mentioned as an important reason for suffering. Cognitive symptoms caused much suffering. Patients with psychiatric symptoms emphasised the burden of their suffering. The side effects of medical treatment for psychiatric conditions and cancer were named as an additional cause for suffering.



Table 1 Characteristics of patients explicitly requesting assistance in dying

Patient number	Gender	Age (years)	Diagnosis	Years since diagnosis	Follow-up	Survival after interview (days)
1	Female	53	Lung cancer	4	EAS	61
2	Male	43	Liver cancer	0.25	EAS	12
3	Male	88	Colon cancer	0.5	EAS	1
4	Male	88	M. Parkinson	4	Pneumonia	122
5	Male	54	Gastric cancer	0.25	EAS	5
6	Female	71	Gall bladder cancer	1	EAS	34
7	Male	43	Depression	19	Alive	
8	Female	92	Tired of life	2	Alive	
9	Female	57	Sigmoid cancer	4	EAS	3
10	Male	65	Depression	6	Alive (ECT)	
11	Female	49	Breast cancer	3	EAS	15
12	Male	80	Parotid cancer	2	Not eating or drinking	10
13	Female	70	Parkinson's disease	2	EAS	164
14	Male	32	Schizophrenia	9	Alive	
15	Female	65	Breast cancer	9	EAS	29
16	Female	55	Nasopharyngeal cancer	1	EAS	195
17	Female	80	Tired of life	2	Alive	
18	Female	55	Ovarian cancer	3	Palliative sedation	10
19	Female	89	Completed life	8	Alive	
20	Female	62	Anxiety disorder	48	Alive	
21	Male	62	Kidney cancer	9	EAS	60
22	Male	83	Lung cancer	0.25	EAS	5
23	Female	80	Pain syndrome	8	EAS	2
24	Male	75	Motor neuron disease	1	EAS	80
25	Female	77	Pain syndrome	3	EAS	54
26	Female	94	Tired of life	0.5	Alive	
27	Male	77	Bladder cancer	0.5	EAS	8
28	Female	65	Pain syndrome	2	EAS	24
29	Male	61	Alzheimer's disease	3	EAS	172
30	Male	65	Motor neuron disease	1	EAS	86
31	Female	76	Motor neuron disease	2	EAS	8

EAS = euthanasia or physician-assisted suicide

Life expectancy	Residence	Education	Occupation	Marital status	Number of children	Religion
14 days	Hospice	Intermediate	Administrator	Married	2	-
20 days	Hospice	High	Teacher	Single	0	Humanism
14 days	Hospice	Intermediate	Director	Widower	2	-
6 months	Nursing home	Basic	Farmer	Married	7	Catholic
1 month	Home	High	Manager	Married	2	-
2 months	Home	Basic	Housewife	Widow	3	-
-	Home	High	Housewife	Single	0	Buddhism
-	Home	Intermediate	Administrator	Widow	0	-
1 month	Home	High	Lawyer	Divorced	2	-
-	Home	High	Director	Divorced	2	-
2 months	Home	High	Manager	Married	2	-
4 months	Home	High	Teacher	Widower	2	Agnostic
Unknown	Home	High	Teacher	Married	2	Humanist
-	Home	Basic	Housewife	Single	0	-
2 days	Home	Intermediate	Home care	Divorced	2	There is more
2 weeks	Home	Intermediate	Accountant	Married	3	Protestant
-	Home	Intermediate	Café owner	Widow	3	My own
2 weeks	Hospital	Intermediate	Secretary	Married	3	-
-	Home	Intermediate	Nun	Single	0	-
-	Home	Basic	Author	Single	0	Atheist
1 month	Home	High	Manager	Married	0	Secular
1 month	Home	High	Businessman	Married	4	-
Unknown	Nursing home	Intermediate	Housewife	Married	4	-
4 days	Home	Basic	Manager	Married	5	-
Unknown	Home	High	Psychotherapist	Widow	3	Humanist
-	Nursing home	Basic	Needlewoman	Widow	1	Catholic
2 weeks	Home	Intermediate	Salesman	Married	2	-
1 month	Hospice	Basic	Housewife	Widow	2	-
Unknown	Home	High	Director	Married	2	-
1 month	Home	Intermediate	Real estate agent	Married	3	Catholic
Unknown	Nursing home	Intermediate	Housewife	Widow	2	Protestant

Table 2 Remarks about unbearable suffering made by patients who explicitly requested assistance in dying

	Theme	Patient	Remarks
<b>Medical</b>			
1.1a	Illness-related physical symptoms	31	I have fecal incontinence. I can no longer swallow, and in hot weather I really envy people who can drink.
1.1b	Fatigue	12	The way to my bed is endless, and finally I get there. It takes a lot of energy, but once I'm in bed, it takes an hour just to gather my strength again.
1.1c	Pain	28	I am in pain all the time, I am in pain at night, I wake up with pain and I go to bed with pain. If they could take away half my pain I wouldn't be thinking about euthanasia.
1.2	Cognitive symptoms	9	The last few days even the news doesn't interest me anymore, I have less interest in the outside world. My brain no longer works, and to me that is a part of human dignity and of unbearable suffering. I want to function normally, and if I can't do that...
1.3	Psychiatric symptoms	7	I suffer so much that I can't recall when life was lovely and happy. My life is hell. My life is inhuman. I have such deep pain inside.
1.4	Misery due to medical treatment	11	I was simply nauseous, and my energy was just running out. And I said that I wished that, just for a short period of time, I could eat normally and not have to fight to keep it down, and that I wanted to have a little more energy. Then I stopped the chemo, and indeed I had that improvement.
1.5	Decline	29	I can no longer bear the undermining nature of my disease; there are moments when I can't find a single word in my brain.
<b>Psycho-emotional</b>			
2.1	Loss of sense of self	13	I want to present myself as being as normal as possible, but everybody notices it: I stumble and I am slow, and that is just not me because I always was a nimble girl.
2.2	Negatively colored feelings	17	I am tired of life, and that has to do with my marriage, which was difficult. Not every day, but regularly, and that was not so pleasant. I was going to write it all down, but I am so very tired.
2.3	Fear of future suffering	21	Finally the illness that dominates everything will wipe out all life has to offer me, what I feared most is exactly what will happen to me. I won't belong anymore, the emptiness of existence, the lack of independence, being unable to do things myself, being at the mercy of others whom I will have to beg to do the things I need in a way that's suitable for me.
2.4	Dependency	26	I can't do anything anymore, they leave me lying here until ten o'clock and they only wash me when they feel like it.
2.5	Autonomy	27	I say: I have made my decision. I don't want you to treat me any longer. Someone says, now you are probably too weak for chemo. I say: if I'm not too weak and they want to give me chemo, I will refuse it, because in the little time that is left to me I want quality of life, not quantity of life. I decided that year ago: if this were to overcome me, then that's what I would choose.

2.6	Mental exhaustion	2	Mentally I am completely exhausted. I can't fight it anymore.
<b>Socio-environmental</b>			
3.1	Loss of being socially significant	3	I was a very handy man: there were all kind of odd jobs to be done in the home for the elderly and I enjoyed doing them. Then I felt useful to this society. I can't do it anymore, I can't do anything anymore, but I lived a worthy life...
3.2	Communication problems	30	When he is with his friends, he can't say anything, and that's just the difficulty. He likes me to be there because when he can't manage to communicate he feels so unhappy. The conversation flags and with, um, such a device, most conversation is almost impossible. Just talking to him, I notice that you really must never ask him anything, you must just tell him things, and only ask questions that he can answer with yes or no.
3.3	Discontent about residential circumstances and quality of care	24	I will decide for myself as long as I can. I don't want to go to a nursing home, we have agreed on that. It would be the end of me.
3.4	Being a burden	28	I have become so weak because of the pain. I can't walk anymore, I can't eat anymore. My children have suffered enough. I don't want them to go through this again. Everybody has to lose their parents someday anyway.
3.5	Loneliness	8	The home help comes once a month. Even though I look healthy, I have so much grief because I have lost everybody, your parents, your husband, and your sisters and my brother was shot dead by the Germans. Everything is gone.
3.6	Biography	10	...claustrophobia of my existence. To put it simply, it is insight without perspective. Never in my life have I felt any love. If there had been some warmth and love and safety, I could have grown.
<b>Existential</b>			
4.1	Limitation of activities	25	I can't drive anymore. I loved to paint and draw, but I can't do that either anymore. Everything I enjoyed is gone. And then, my sight became worse...
4.2	Hopelessness	16	You lie in bed and none of the normal functions come back. They will never come back and it will only get worse.
4.3	Pointlessness	5	I'm not interested at all anymore, I just lie here, and what's the point? There isn't any. I no longer read. Not books, not newspapers. I have CDs and the walkman right here. Well, I've listened to, um, two CDs, and that's enough. And yet I really loved music, but it's all over. I'm just not interested anymore.
4.4	Being tired of life	19	I think that my life is absolutely completed. I don't know what else I could want.

Table 3 Themes, categories, and codes of suffering named by patients explicitly requesting assistance in dying

Themes	Categories	Codes
Medical	Physical symptoms	General symptoms: pain, fatigue, general malaise, feeling miserable, physical deterioration, changed appearance Gastrointestinal symptoms: eating and drinking problems, anorexia, nausea, vomiting, loss of weight, defecation problems Nervous and locomotor symptoms: deterioration of locomotor function, mobility, and coordination; loss of balance; dizziness Dyspnea Incontinence
	Cognitive symptoms	Confrontations with cognitive deterioration, deterioration of ready knowledge, inability to concentrate, inability to participate in conversations, slow-wittedness, loss of memory
	Psychiatric symptoms	Loss of emotional control, loss of emotions, insomnia, de-realization, depersonalization, suicidal ideation, depression, identity crisis, fear, addiction
	Effects of medical treatment	Side effects of chemotherapy, radiotherapy, psycho pharmaceuticals, and morphine. Complications of operations
	Decline	Physical, cognitive, and emotional
Psycho-emotional	Loss of self	Loss of the following: Autonomy: independence and being in control Expression of personal traits: social-mindedness, readiness to help others, being of significance, caring, pride in achievements Communication style: considerate of the views of others, open Specific personality descriptors: modest, honest, loyal, consistent, interested, rational, humorous, relativistic, optimistic, uncomplaining, not overly emotional Favorite activities: active outdoor events and “enjoying life”, e.g., going out for dinner, etc.
	Negative feelings	Impotence, bitterness, misery, emptiness, suffering, emotional pain, disappointment, sadness

	Fears of future suffering	<p>The course of the illness and dying: getting worse, uncontrollable symptoms, a horrible death</p> <p>Cognitive decline: deterioration, loss of control of the mind, loss of community, becoming insane with fear, being unable to recognize surroundings</p> <p>Consequences of palliation: side effects of treatment, including morphine</p> <p>Physical decline: deterioration, dullness, urinary incontinence, mechanical ventilation</p> <p>Physical symptoms: nausea, pain, choking, dyspnea</p> <p>Loss of self-determination: being totally unable to do anything, loss of control, vegetative state, being bedridden.</p> <p>Emotional aspects: suffering, anxiety</p>
	Dependency	Being dependent, loss of physical functions of everyday living, being bedridden
	Loss of autonomy	<p>The way others treat you: patient role, being treated as a hothouse plant, not being seen as a human being, being pressured to make decisions</p> <p>Loss of self-determination: loss of direction, loss of making your own decisions, loss of independence, impaired daily functioning</p> <p>Desire to control death: not wanting to experience the end stage of the disease, not wanting to suffer to the end, desire to have a say about your own dying, wanting your preferred way of dying, wanting to die with dignity, wanting no prolonged dying, desire to die at home, wishing to have some influence on the memories left behind</p>
	Being worn out	Not being able to stand it anymore, demoralization, being so tired, exhausted by the treatments, tired of fighting the illness
Socio-environmental	Loss of social significance	<p>Not being significant for society or loved ones</p> <p>Loss of social, occupational, and family roles, status</p>
	Communicative problems	Inability to participate in conversation, inability to communicate
	Discontent about residential circumstances and quality of care	<p>Residential: being unable to go home, nursing home as a prospect, unsuitable living conditions</p> <p>Quality of care: poor quality of professional care, disappointment in informal care</p>
	Being a burden	Being a psychological or physical burden to the next of kin and the formal and informal caregivers
	Loneliness	Loss of loved ones, withdrawal, isolation, being left alone
	Biographical aspects	Family history, occupational history, autobiography, social background, bad marriage, sexual abuse, family trauma (e.g., war)

Existential	Loss of important and pleasurable activities	Being unable to participate
	Hopelessness	Absence of any hope of improvement, absence or degrading future prospects, nature and progress of the disease, unsuccessful suicide attempts
	Pointlessness	Loss of joie de vivre, loss of purpose in life, loss of the will to live
	Life is over	Being tired of life or weary of living, a feeling that your life is completed

### The psycho-emotional context

The six subcategories in the psycho-emotional theme were loss of self, negative feelings, fear of future suffering, dependency, loss of autonomy and mental exhaustion. With the exception of patients with a psychiatric diagnosis, the patients described themselves as autonomous persons aiming to be significant to others, in favour of communicating with others, preferring an active lifestyle. Loss of self was a great cause of suffering (Table 2). Some patients expressed the presence of negative feelings that took centre stage in their minds and thus added to their suffering. The patients mentioned a wide range of fears of future suffering. These fears were related to the course of illnesses, physical symptoms, the process of dying, decline, loss self-determination or anxiety. Sometimes loss of autonomy was experienced as a threat to personality. Being treated as a patient especially when others had to take over everyday tasks or when being bedridden was described as suffering. The wish to have a say about their death was another expression of the desire for autonomy. Many patients suffered from mental exhaustion.

### The socio-environmental context

The six subcategories in the socio-environmental theme were loss of social significance, communicative problems, discontent with residential circumstances and quality of care, being a burden, loneliness and biographical aspects. The patients mentioned loss of social significance often. Exclusively patients with motor neuron disease or dementia mentioned communication problems, but such problems were of minor importance compared with other symptoms of these diseases. A prospect of a possible transfer to a nursing home added to suffering. Patients who had high-quality informal care and strong family connections and who had been the central figures in their families were particularly concerned about being a burden. Those who were widowed, patients with psychiatric problems and patients forced to live separately from their partners were lonely. Aspects of the patients' past, such as sexual abuse, a bad marriage, or childhood in a war camp had a very individual influence on their suffering.

### The existential context

All patients experienced existential suffering. There were four categories within



this theme: loss of important and pleasurable activities, hopelessness, pointlessness and being tired of life. Loss of important and pleasurable activities comprised a long list of activities, which included managing the household, looking after the grandchildren, gardening, going out for dinner, companionship, reading, playing tennis, travelling abroad, listening to music and singing in a choir, being significant to others and having a wonderful job. All patients mentioned hopelessness. Hopelessness inevitably gave rise to feelings of pointlessness that resulted in being tired of life.

### **The patients' perspectives on unbearable suffering**

Patients who, in contrast with the other patients, emphasised continuous feelings of unbearable suffering, saying “to be unable to enjoy anything anymore”, had a psychiatric diagnosis. Subcategories of existential and psycho-emotional themes contributed greatly to the perception of suffering becoming unbearable (Table 4). As an 80-year-old man, a former mathematics teacher and musician put it: “I can’t do anything anymore, I used to play music, participated in various clubs, all so very companionable, I had to say farewell to all of it. It feels so awful just waiting to become bedridden and then waiting to die”. All patients considered hopelessness to be a main factor in the perception of unbearableness. This is illustrated by a 55-year-old woman with nasopharyngeal cancer: “You lie on a bed and none of the normal functions come back. They will never come back and it will only get worse”. In addition, patients placed unbearable suffering in the broader context of their personality characteristics. They explained how the irreversible consequences of disease or ageing resulted in loss of self, loss of autonomy and mental exhaustion until they felt themselves no longer the persons they used to be. This is exemplified by a 53-year-old woman with lung cancer: “I lost my dignity, lying in bed in diapers, I am no longer the independent person I used to be”. In the medical theme, untreatable neurological pain, fatigue, decline and particularly psychiatric symptoms made the suffering unbearable. A 65-year-old woman with neuropathic pain, on maximum analgesic treatment, expressed this as: “I am in pain all the time, I am in pain at night, I wake up with pain and I go to bed with pain. If they could only take away half my pain I wouldn’t be thinking about euthanasia”. In the socio-environmental theme, loneliness and being a burden often contributed to unbearable suffering, but these elements mostly were of minor importance. Most patients, when asked about unbearable suffering, made up a balance of their past, their present and their expectations of the future. When this balance gave rise to feelings of hopelessness (often combined with feelings of pointlessness and being tired of life), they considered their suffering unbearable. As a 48-year-old woman put it: “It is such an aggressive form of cancer. I saw all my energy going down the drain what I could still do last week I can’t do at all now. I really enjoyed my life, but now I have just to wait and see how things go and what death will look like”. This was in great contrast with one 94-year-old woman, who was in excellent psycho-emotional condition and had no classifiable disease. She was

living in a caring environment, communicating in a lively way and e-mailing with her extensive international network. She requested assistance in dying for reasons of being ready to quit life without any suffering at all.

Table 4 Occurrence in themes and subcategories of unbearable suffering

Theme	<i>n</i> *	Subcategory	<i>n</i>	Code	<i>n</i>
Medical	29	Physical symptoms	29	Fatigue	10
				Pain	6
				Feeling miserable	1
				Nausea	1
				Vomiting	1
				Eating or drinking problems	4
				Dyspnea	3
				Locomotor function	5
				Incontinence	2
		Psychiatric symptoms	5		
		Complications of treatment	6		
		Decline	20	Physical	13
Psycho-emotional	29			Cognitive	10
				Emotional	1
		Loss of self	17		
		Negative emotions	17		
		Biographical aspects	1		
		Fear of future suffering	5		
		Dependency	12		
		Loss of autonomy	18		
Socio-environmental	20	Being worn out	16		
		Loss of social significance	1		
		Communication problems	3		
		Discontent with residential situation or quality of care	5		
		Being a burden	13		
		Loneliness	8		
Existential	31	Hopelessness	30		
		Limitation of activities	23		
		Pointlessness	17		
		Tired of life	17		

\**n* = number of patients who mentioned the theme, category, or code

## Discussion

This study has brought to light the fact that unbearable suffering, from the perspective of patients who explicitly request EAS, is the outcome of an intensive process that originates in the symptoms of illness or ageing. The same elements from the medical, psycho-emotional, socio-environmental and existential themes, as we identified earlier in a literature review,<sup>11</sup> appeared to cause suffering. Especially elements from the existential and psycho-emotional themes contributed to unbearable suffering and hopelessness was at the centre. Patients considered physical suffering less important, as earlier studies also demonstrate.<sup>13;16-22</sup> This may suggest that physical suffering had been palliated before the experience of unbearable suffering and the request for EAS came about. It became evident that uncontrollable physical symptoms, such as fatigue and neurological pain, contributed considerably to unbearable suffering through its negative effects on the motivations for living. For most patients who request EAS, time is limited; this affects the possible treatment of elements of unbearable suffering. It strengthens the importance of an early detection and treatment of symptoms like negative feelings, fears of future suffering, being worn out, loss of autonomy, loss of social significance, loss of activities, pointlessness and being tired of life to prevent suffering becoming unbearable.

Our study made obvious that the patient's request for EAS does not exclusively originate in feelings of unbearable suffering. In agreement with earlier findings, most patients did not experience unbearable suffering continuously.<sup>13</sup> In addition, we found that patients who emphasised continuous feelings of unbearable suffering were diagnosed with a depression. Patients without a depression held the opinion that they were in an unbearable situation and named reasons to ask for assistance in dying in terms of unbearable suffering. Earlier research showed that a depressed mood is associated with a four times higher risk of a request for EAS.<sup>23</sup> This underlines the importance of ruling out a depression before agreeing to a request. In agreement with earlier studies, physicians were unwilling to cooperate in requests with psychiatric (co)diagnosis.<sup>24;25</sup> We found that patients evaluated their suffering in the context of personality characteristics, life history and existential motivations. The moment this evaluation evoked strong feelings of hopelessness, they perceived their suffering as unbearable. This progression of suffering to the point of hopelessness is compatible with a theoretical model of unbearable suffering,<sup>26</sup> which implies that the outcome of unbearable suffering can only be fully understood from the individual patient's perspective and not so much from the burden of physical signs and symptoms. Individual patients emphasised the loss of all that life made worth living, felt that they were no longer the persons they used to be -Cassell's disintegration of the person<sup>1</sup>- and had no hope of improvement.

Our study underlines that it is possible to carry out research with patients in end-of-life situations. Researchers and practitioners have long been concerned about burdening vulnerable patients in the last phase of their lives with research. Only

in the past decade has such research become acceptable.<sup>27,28</sup> We found physicians prepared to ask terminally ill patients to participate in research. Patients found it useful to know that others would benefit from their experiences.

The study has some limitations. The findings should be placed in the context that unbearable suffering is among the criteria of lawful EAS in the Netherlands. Consequently, patients might feel urged to express the reasons for their request in terms of ‘unbearable suffering’. It is unclear how this legal aspect affects the patients’ phrasing of their request. It is unknown whether the participating physicians selected patients in view of specific elements of suffering or unbearable suffering. We do not know what kind of patients refused participation and whether refusal was related to the nature of suffering.

We hypothesise that, while suffering is rooted in the symptoms of illness or ageing, the existential and psycho-emotional themes determine how much hope there is and whether the patient is able to bear the suffering. Unbearable suffering can only be understood in the continuum of the patient’s perspectives on the past, the present and expectations of the future. Without hopelessness, there is no perception of unbearable suffering. These findings have implications well beyond decisions about EAS. Physicians, nurses and other healthcare professionals who practice palliative care should be able to understand patients’ existential and psycho-emotional suffering (including the hopelessness) in an early stage to prevent suffering from becoming unbearable.

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## **Ethics approval**

The study was approved by the Research Ethics Committee at the Radboud University Nijmegen


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‘Als je niet weet hoe te sterven,  
wees dan niet ongerust de natuur zal u  
in een oogwenk op de hoogte brengen.  
De natuur zal dit doen op die wijze  
die voor u precies de juiste is:  
maakt u zich maar niet ongerust’

Montaigne, 16e eeuw



# *Chapter 4*

Perspectives of decision-making in requests for euthanasia.  
A qualitative research among patients, relatives, and  
treating physicians in The Netherlands

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## Abstract

**Background** Euthanasia has been legally performed in the Netherlands since 2002. Respect for patient's autonomy is the underpinning ethical principal. However, patients have no right to euthanasia, and physicians have no obligation to provide it. Although over 3000 cases are conducted per year in the Netherlands, there is little known about how decision-making occurs and no guidance to support this difficult aspect of clinical practice.

**Aim** To explore the decision-making process in cases where patients request euthanasia and understand the different themes relevant to optimise this decision-making process.

**Design** A qualitative thematic analysis of interviews with patients making explicit requests for euthanasia, most-involved relative(s) and treating physician.

**Participants/setting:** Thirty-two cases, 31 relatives and 28 treating physicians. Settings were patients' and relatives' homes and physicians' offices.

**Results** Five main themes emerged: (1) initiation of sharing views and values about euthanasia, (2) building relationships as part of the negotiation, (3) fulfilling legal requirements, (4) detailed work of preparing and performing euthanasia and (5) aftercare and closing.

**Conclusions** A patient's request for euthanasia entails a complex process that demands emotional work by all participants. It is characterised by an intensive period of sharing information, relationship building and negotiation in order to reach agreement. We hypothesise that making decisions about euthanasia demands a proactive approach towards participants' preferences and values regarding end of life, towards the needs of relatives, towards the burden placed on physicians and a careful attention to shared decision-making. Future research should address the communicational skills professionals require for such complex decision-making.

## Background

Worldwide, irrespective of legalisation, patients in end-of-life situations do request euthanasia and physician-assisted suicide (EAS). Debates about the topic are often based on moral and personal views. Requests are often complicated to handle, and careful exploration and communication are required. In the Netherlands, since 2002, EAS can be legally performed on condition that six rules of due care

are adhered to<sup>1</sup> (Box 1) is carried out by a physician and reported to one of the five Regional Review Committees.<sup>2</sup> The law foresees no guidance about how physician and patient make their decision nor prescribes details about conducting the procedure. Although respect for patient autonomy is one of the most important underlying ethical principles, patients have no right to EAS and physicians have no obligation to provide it.<sup>3</sup> The legal framework increased the transparency on decision-making in EAS<sup>4-7</sup> and gave way to a unique systematic periodic and empirical research on end-of-life decision-making. Research made evident that in general, patients brought up the topic themselves<sup>6</sup> and were not influenced by others.<sup>8,9</sup> It was found that the assessment of a request being voluntary and well considered was sometimes complicated,<sup>10</sup> and differences in views on unbearable suffering and hopelessness between patients and attending physicians were important reasons for refusal of a request.<sup>11;12</sup> It became evident that while some physicians hold the opinion that palliative care was as an alternative for EAS,<sup>13-15</sup> others found that in three-quarters of the requests, there were no palliative options left to diminish unbearable suffering.<sup>16</sup> No research was found about how EAS decisions were taken in practice. The special nature of the act makes it of major importance that participants by sharing information, perspectives, thoughts and feelings and by mutual respect of autonomy and deliberation find their way through this difficult decision even in cases where there are differences in opinion. Our experience in EAS in clinical practice has directed us to SDM based on choice, option and decision-talk as described by Elwyn et al.<sup>17</sup> as the best possible approach to deal with the underlying complexities. Shared decision-making respects patient autonomy and promotes patient engagement.<sup>18;19</sup> It is an interactive process in which patients and health professionals collaborate in decision-making, based on the best available evidence and personal preferences; it highlights the risks and benefits of all available options, including the option of taking no action.<sup>20-22</sup> SDM is not (yet) widely implemented.<sup>23</sup> However, Dutch physicians have managed to come to shared-decisions with patients about EAS requests (Box 1). Criteria for euthanasia or physician-assisted suicide We can profit from their experiences and, in line with Schön's Reflection in action,<sup>24</sup> use their experience to understand how complex decision-making occurs in practice. The aims of this study were to explore the decision-making process in cases where patients ask their physician for EAS and to understand the different themes relevant to optimise this decision-making process.

## Definitions

In 1985 a State Committee, installed by the Dutch Health Council, defined euthanasia as 'the intentional termination of life by someone other than the person concerned at his or her request' and assisted suicide as 'intentionally assisting in a suicide of another person or procuring for that other person the means'.<sup>25</sup> A Support and Consultation for Euthanasia (SCEN) specialist is an independent

doctor trained to provide SCEN in the Netherlands.

**Box 1** Criteria for euthanasia or physician-assisted suicide

Euthanasia or physician-assisted suicide has been legal in the Netherlands since 2002, provided that the six criteria for due care of Article 293, paragraph 2, of the Dutch Penal Code<sup>1</sup> are met.

The treating physician must:

- a. Be convinced that the patient's request is voluntary and well-considered
- b. Be convinced that the patient's suffering is unbearable and hopeless
- c. Inform the patient about his/her situation and prospects
- d. Be convinced, as the patient must also be, that there is no other reasonable solution for his/her situation
- e. Consult at least one other independent doctor, who must see the patient and give his/her written opinion about whether the first four criteria have been satisfied
- f. Use all due care in terminating the life or assisting in the suicide

## Methods

### Study design

We performed a qualitative, in-depth interview study with patients who had explicitly requested EAS, their most involved relatives and their treating physicians.<sup>26;27</sup> We included patients whose request was granted and patients whose request was declined. Patients were interviewed after they had made an explicit request, relatives and treating physicians approximately 4 weeks after the patient's death, or as soon as it was obvious that the request would not be granted. Thus, we performed a multiple- perspective,<sup>28</sup> serial interview study<sup>29</sup> and interviewed relative and physician shortly after the performance enabling them to reflect on the burdensome period as a whole. Field notes were made immediately after each interview. We collected demographic data before the interviews and analysed the written reports of the independent physicians that are required to be consulted. All interviews were audiotaped and transcribed. The Research Ethics Committee of the Radboud University Nijmegen Medical Centre approved the study. All participants gave their informed consent.

### Recruitment and patient selection

We recruited potential patients and participants in following several selection pathways. We worked with the network of SCEN in the Netherlands. We also contacted a hospice, a hospital and a nursing home and placed a notice in the journal *Right to Die – NL*, inviting patients to contact us if they wished to participate in this study.

### Interviews

We planned to interview patients at home for no longer than an hour. When possible, we interviewed patients alone to ensure they felt free to voice their own views. The interviewer (M.D.) is an experienced female general practitioner (GP)

and SCEN specialist. The topic guide examined the decision-making processes that took place in a request for EAS (Box 2).

Box 2 Topic guide

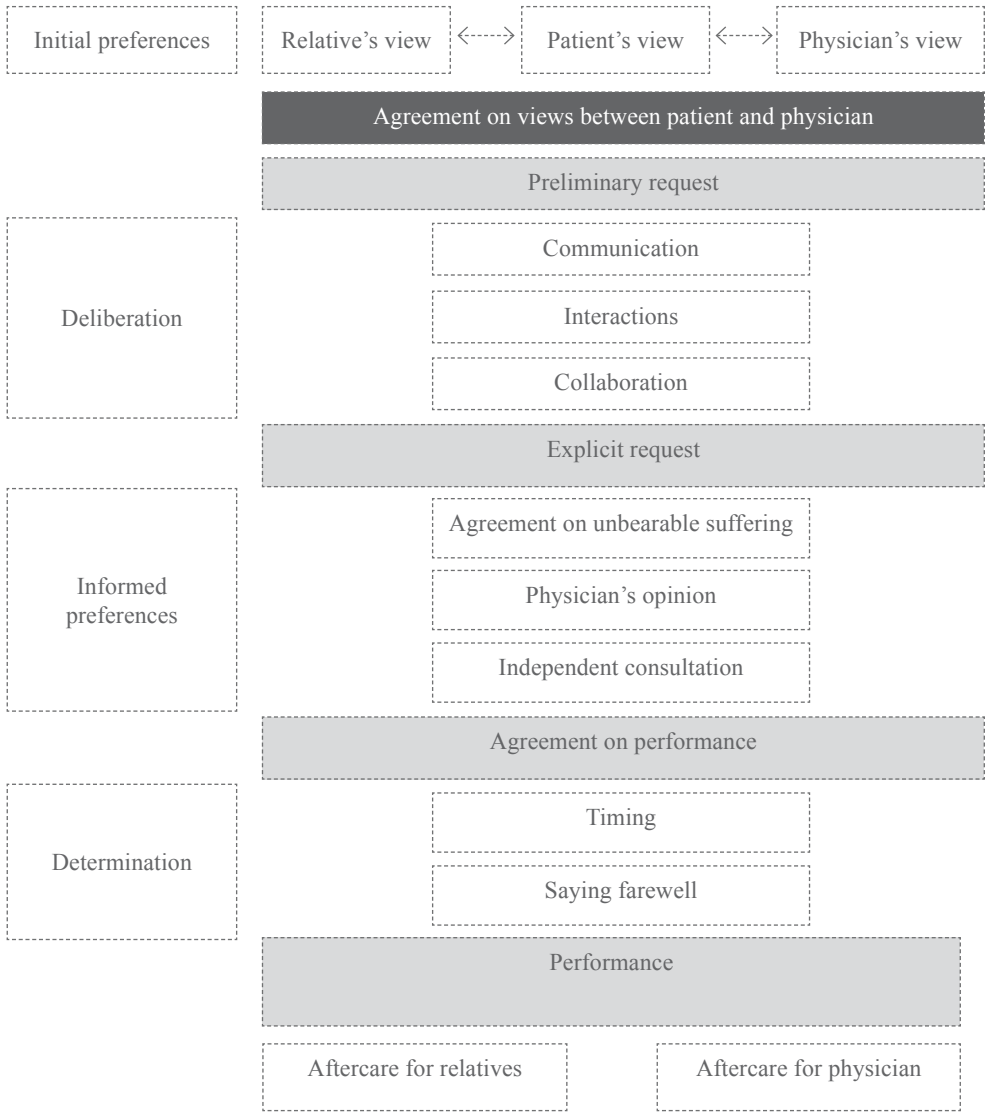
- Development of patients' request for EAS
- Opinion on EAS (relatives and physicians)
- Talks with relatives
- Talks with attending physicians
- Factors that made the request topical
- Effect of the request upon relative and physician
- Planning of the performance
- Retrospection on the period ( i.e. course, emotions, decision-making)

### Data analysis

We used the constant comparison approach to analyse (1) the interview data and (2) the reports of the independent physicians, supported by the use of ATLAS.ti version 5.5.<sup>30;31</sup> We avoided using pre-set categories and explored the data as a whole.<sup>32;33</sup> Two researchers (MD and MS) independently coded data for five clusters of participants (patient, relative, physician and consultant). The codes were descriptive at the level of participant statements. Next, MD and MS compared codes and discussed them with a third researcher (MV). They agreed on code modifications, mergers and additions and developed a revised coding scheme. MD and MS coded all the remaining transcripts, comparing codes after every fifth case. When no more new codes were required, we considered that saturation had been reached. At this stage, no further participants were recruited for interviews. MD and MS independently grouped codes referring to the same phenomenon to form provisional categories and themes. The analysts and the peer group discussed these categories and themes. The peer group included two GPs (CW and MD), a sociologist (MV), an ethicist (WD) and a palliative care specialist (KV). MD then reapplied the thematic structure to the data. The peer group, joined by (GE), expert on shared decision-making, considered whether the practice described by the participants could be compared to the approach known as shared decision-making.<sup>23</sup> MD proposed an optimal process for decision-making in EAS on the basis of the analysis (Figure 1).



Figure 1 A model for distributed, shared-decision-making in euthanasia and physician-assisted suicide



## Results

We identified 45 patients for interview between April 2008 and July 2009. We excluded 12 patients because they had not explicitly requested EAS. Two patients died before we could interview them. However, in one of these cases, the relative and treating physician requested interviews. We therefore included 32 cases and conducted a total of 90 interviews as follows: 31 with patients, 31 with relatives and 28 with treating physicians. In addition, we retrieved 24 written reports of



consulted independent physicians (Table 1). Three patients had no close relatives, and two patients with psychiatric problems refused permission to approach their relatives because they had not informed them about their request. In three cases, a second relative was willing, with the consent of the patient, to be interviewed. In four cases, the treating physicians declined interviews because they hold the opinion that their patients did not meet the requirement of hopeless and unbearable suffering.

### **Participant characteristics**

We included 32 cases, 15 men (aged 32–96 years) and 17 women (aged 49–94 years). They varied in diagnosis, educational level, marital and occupational status. Fourteen patients were diagnosed with cancer, six with a degenerative neurological disease, four with a psychiatric disease, three had a chronic pain syndrome, one had heart failure and four reported being ‘tired of life’ (Table 1). Twenty-four patients lived at home, five were in a hospice, two were in a nursing home and one had been admitted to a hospital (Appendix 1). All carers were relatives, aged 26–77 years (19 women, of whom 7 were wives, and 12 men, of whom 5 were husbands). Their responsibility varied widely (Table 1). The requests of 11 cases were not granted. In four cases, the patients reported ‘being tired of life’ is ruled out as a basis for EAS by the Dutch Supreme Court.<sup>34</sup> In four cases, a psychiatric disorder was the cause of the patients’ suffering. Such requests are seldom granted, whereas physicians struggle by the death wish being driven by the disorder and with the possibility of recovery.<sup>35</sup> The other refusals were due to a difference of opinion about ‘unbearable suffering’, doubt about decision-making competence and the policy of the residential setting. Most of the 28 interviewed physicians (20 men) were GPs, three were specialists in care of the elderly and one was a psychiatrist. Eight physicians were also SCEN specialists. The male physicians were on average 10 years older than their female colleagues and performed EAS more often (Table 1).

### **Decision-making regarding a request for EAS**

We identified five consecutive phases that can be seen as key themes: 1) initiation of sharing views and values about EAS, 2) building relationships as part of negotiating, 3) fulfilling legal requirements, 4) detailed work of preparing and performing EAS and 5) aftercare and closing (Table 2).

**Theme: initiation of sharing views and values.** All recruited patients declared that they had already viewed EAS positively before the onset of their illness. Their preparation for making a request had started at different times: before becoming ill, when diagnosed with a life-threatening problem or when facing the terminal phase of illness. Personal characteristics, such as a strong wish to have a say over one’s own death, past experiences of medical care and witnessing ‘unbearable suffering’ were cited as reasons for considering EAS. Patients reported a phase of gathering

information, sharing views with relatives and questioning their treating physician, most often their GP, about EAS: *Patient 1: 'Last year when I became ill, I was afraid that I would get brain metastases. I guess I just want to have everything arranged properly for the GP, the family, and myself. I became a member of the euthanasia society and gave my GP a euthanasia directive'*. Only one GP said that he routinely initiated conversations about EAS in the context of end-of-life decision-making, others said that they reacted to patients' requests. Patients reported that early discussions with physicians enabled to prepare themselves for the implications of the request. Patients also reported that early awareness on their part of resistance to EAS allowed them to consider approaching another physician. One GP (Ph16-1), who always declined EAS, made arrangements with a willing colleague: *Physician 16-2: 'I barely bothered with the physical aspects. Ph16-1 stayed involved. The way to euthanasia for me has always been a path that needs guidance, and we had agreed that I would take on this task'*.

**Theme: building patient–physician relationship as part of negotiating.** The data showed that the nature and quality of the patient–physician relationship were crucial during decision-making. The patient's request put a strain on the patient–physician relationship – cutting across the usual curative role. When physicians, patients and relatives established effective relationships, positive relational effects resulted, even if initial requests were declined. Effective relationships included mutual respect for autonomy, clear communication and collaboration. When patients were aware of the burden that providing EAS placed on the physician, this improved relationships: *Patient 30: 'It is really hard for him; he agreed, and he will never deal with anything beforehand. But I do think it's better if one makes a statement. And he did, even though it was not easy for him. He showed his commitment. That is important to me, that I appreciate'*. The participants valued recurrent, profound, open communication, demonstrating respect for each other's views and values: *Relative 13: 'He visited us more than 10 times I guess. The first time, he immediately said, yes, in principle you are incurably ill, there is no treatment, and you are of sound mind, so it should be possible. So we'll talk about it. And we did; in 2008 he came again and again to continue talking'*. Communication was facilitated when physicians showed empathy, were clear about their boundaries and helped patients organise their thoughts and express their feelings. Patients reported barriers when they were patronised, when they were denied the freedom to voice preferences and when physicians only considered medical issues. Physicians reported difficult coping when patients or relatives made demands that they felt went beyond what had been mutually negotiated: *Physician 5: 'I had been tempted: it was planned for Wednesday. I was led astray. He was not being unpleasant, you understand, but I realised I that had my doubts and I felt trapped'*. Participants who were satisfied about the process mentioned the sharing of information, the involvement of relatives and decisions made together. Discontentment was reported when participants were not well-

informed or physicians were either patronising or servile: *Physician 4: 'In the end I just couldn't do it. I felt guilty because I had said that when it gets to that point I'll do it. But I could not get myself to the point where I thought, now I'm going to do it. The person who helps a patient die has to live on, not the patient'*. There were large differences in the roles of relatives. Positive outcomes were noted when relatives were supportive and respectful. Relatives were not in a position to determine the final decision, but a lack of support from relatives impeded decision-making: *Relative 25-2: 'Without her husband knowing – he really didn't want to have anything to do with it – she and my sister filled in the papers together. But her husband unexpectedly appeared. He did not agree at all that she was already doing this, of course. He believed that there were still possibilities, but for her it was already over because she knew she would never recover'*.

Table 1 Participant characteristics in cases where patients explicitly requested euthanasia or physician-assisted suicide

Patient's characteristics				
Gender	Diagnoses(number)	Age in years	Number refused	Reason for refusal
15 Male	Cancer(7), heart failure(1), degenerative neurological disease(4), psychiatric disease(3)	32 – 96	5	Opinion about suffering, competence, treatment options
17 Female	Cancer(7), degenerative neurological disease(2), pain syndrome(3), tired of life(4), psychiatric disease(1)	49 – 94	6	Hospice's policy, opinion about suffering
Physicians' characteristics				
Gender	Specialisation	SCEN	Age in years	Experience of EAS
20 Male	18 GP 1 Elderly-care 1 Psychiatry	3 1	41 – 64 (55)	Once in 3 years
8 Female	4 GP 2 GP-trainee 2 Elderly-care	2 2	37 – 45 (45)	Once in 5 years
Relatives' characteristics				
Gender	Relation	Age in years	Care in hours a day	
12 Male	5 Husband 5 Son 1 Son-in-law 1 Nephew	52 – 79 31 – 52 62 40	2 – 24 1 – 2 16 0	
17 Female	7 Wife 2 Sister 7 Daughter 1 Granddaughter	49 – 78 56 – 60 26 – 61 27	24 4 – 8 1 – 6 1	

Independent consultants' characteristics		
Gender	Specialisation	Age in years
16 male	11 GP*	49 – 61 (54)
	1 Anaesthesiology	
	3 Elderly-care	
	1 Tropical-care	
7 female	4 GP	48 – 58 (54)
	3 Elderly-care	
*One was not a SCEN consultant		EAS = euthanasia and physician-assisted suicide

**Theme: fulfilling legal requirements.** The data showed that ‘unbearable suffering’ is the core concept that guides decision-making in EAS. In practice, working towards an agreement about ‘unbearable suffering’ begins during the first conversation about EAS between the patient and the physician. Different underlying assumptions affected perceptions of unbearable suffering. Some physicians and consultants believe that existential and social suffering or the feeling of being a burden could not contribute to ‘unbearable suffering’. To others ‘unbearable suffering’ is ruled out if the patient has no physical pain or can still enjoy some aspects of life. Many emphasised that a medical diagnosis, a terminal disease and visible suffering is required before agreement about ‘unbearable suffering’ can occur. Agreement between the patient and the physician about ‘unbearable suffering’ appeared necessary before EAS could proceed. All physicians mentioned carefully assessment whether the patient’s request was voluntary, well considered and durable. The patient’s competence to make a request was given special attention whenever there was a possibility of confusion, dementia or a psychiatric problem such as depression: *Consultant 23: ‘There is a well-considered wish for euthanasia, and third parties had not influenced it. There is hopeless and unbearable suffering, based on feelings of total emptiness, cognitive and physical decline, with the expectation of the inevitable death that was close at hand. The fear of symptoms soon worsening is real, as is risk of complications. His mood is not depressive, but it is one of grieving and loss of control over life’.* The independent physicians consulted provided an assessment of the first four rules of due care, support for the treating physician and, on occasion, a second opinion about the case for EAS. The data showed that the consultation had limited influence on EAS performance. Most physicians decided on their course of action before the independent consultation. The consultant’s positive or negative assessment did not alter the physician’s course of action: *Physician 26: ‘To my mind, the severity of the pain was unbearable and hopeless. We had already tried all the alternatives, then there was a negative SCEN consultation – negative because it was only a matter of existential problems and thus not all criteria of due care were fulfilled. Well, in my opinion they were fulfilled, you could see the unbearable suffering in her eyes, it was hopeless, and there was nothing else that could be done’.*

**Table 2 Themes, categories, and codes about decision-making when patients explicitly requested euthanasia or physician-assisted suicide**

Themes	Categories	Subcategories	Codes
Participants' views of EAS	Patient's view is positive	Positive view before illness or symptoms of old age	EAS fits patient's personality, a say about one's own death, medical experiences, witnessing unbearable suffering. Gathering of knowledge about procedures and possibilities, talk with physician about views, talks with relatives about EAS, euthanasia directive. Positive view becomes explicit request. Explicit request becomes request for performance.
		Positive view after diagnosis	
	Physician's view	Prepared to assist in dying	Physician: never performs EAS on principle for dementia or tired-of-living situations, lacks knowledge about legal possibilities, fears prosecution, looks for alternative treatment options, tries to find a colleague with a positive view. Patient: tries to find a physician with a positive view, tries to find a physician willing to perform EAS, asks relative to assist in dying, considers alternatives for ending his own life.
		Not prepared to assist in dying	
	Relative's view	Opinion of EAS is positive	Respects patient's view, supports patient's request, advocates patient's view during procedure, tries to find another physician, considers assisting in dying, has emotional problem with request, lacks knowledge about EAS.
		Opinion of EAS is negative	Stagnation of decision-making.
Building relationships	Communication	Positive influences	Recurrent, profound, open, space for feelings. Physician: promotes tranquillity, names his own boundaries, helps patient organise thoughts and express emotions, understands patient's unbearable suffering. Patient: communicates explicitly about wish, can make others understand unbearable, involves loved ones.
		Negative influences	Physician: shows no empathy, communicates only medical aspects, attempts to convince patient that suffering is not unbearable, talks to relatives instead of patient, feels pressured. Patient does not: easily talk about feelings, experience open communication, get a chance to make his own choices.

	Collaboration	Effective	<p>Patient: takes initiative for talks about perspectives, the request for EAS, and the request for performance.</p> <p>Patient and physician together: make decisions, discuss the rules of due care, inform involved parties.</p> <p>Physician: initiates communication about end-of-life decision-making, gives information about end-of-life possibilities, about procedures, takes responsibility for the decision-making process, takes the time to discuss the decision with involved parties, assesses patient's suffering, wants to be absolutely sure that the patient wants performance.</p>
		Ineffective	<p>Patient: incomplete knowledge about lack of prospects and lawful EAS.</p> <p>Physician: incomplete knowledge about lawful EAS, sticks to continuation treatment, insists on palliative sedation as an alternative for EAS, sticks to an authoritative or paternalistic role.</p>
	Patient–physician relation	Positive characteristics	<p>Knowing each other, respecting each other, feelings of sympathy, acceptance of differences in opinion. Patient trusts physician.</p> <p>Physician: respects patient's perspectives of unbearable suffering, has a positive view on the patient's right to self-determination, does not want to abandon patient, is able to brush aside negative feeling towards patient.</p>
		Negative characteristics	<p>Physician: opinion about patient's personality characteristics is negative, attitude is authoritative.</p>
	Patient–relative relation	Positive characteristics	<p>Involvement, respect, openness, attention to saying farewell.</p> <p>Supports patient with preparations and alternatives in case request is refused.</p>
		Negative characteristics	<p>Not respecting patient's views.</p>
	Relative–physician relation	Positive characteristics	<p>Trusts physician, values dedication and support of physician, understands burden on physician.</p>
		Negative characteristics	<p>Lack of knowledge about legal EAS, pressuring physician, demands a SCEN consultation, expects physician to perform EAS without reporting, differences in view of unbearable, considers finding another physician.</p>

	Influences on perception of unbearable suffering	Visibility, understandability, subjectivity, response shift. Opinion that there is no unbearable suffering when: there is no pain, a patient still enjoys things, suffering is existential, socio-environmental, implies feelings of being a burden, immobility, deafness, or impairment of sight.
Fulfilment of rules of due care in daily practice	Factors influencing opinion of fulfilment of rules of due care	Voluntariness of request, lasting and well-considered request, hopelessness of the situation = absence of options for treatment, agreement on unbearable suffering, differences in views of unbearable suffering between patient, physician, and consultant. Competence: absence of delirium, dementia, psychiatric diagnosis. Optimal palliative treatment. Presence of medical diagnosis, terminal disease, depression, Physician's Incomplete knowledge of legal possibilities, fear for prosecution.
	Independent consultant	Consultation brings about tension for patient and relative. Roles: consultation, support, second opinion, expert. Performance: promised before consultation, despite consultant's negative opinion.
	Timing	Request for performance, performance day.
Performance	Saying farewell	People involved informed, rituals, saying goodbye.
	Performance	Method, determination of patient, physician is in charge.
Aftercare	Relative's reflections	Need of time and space. Difficulties accepting illness, request, speed. Death on appointment is bizarre. Unnatural way to say farewell. Emotional burden, taboo by environment. Eventually looking back with positive feelings. Importance of follow-up (interview as chance to reflect).
	Physician's reflections	EAS is a burden. Not wanting to abandon the patient. Preference for palliative sedation. Need of time and space. Problem when feeling pressured. Importance of taking good care of yourself. Appreciation of support. Importance of follow-up appointment with relatives. Eventually looking back with positive feelings. Interview offers chance for reflection.

EAS = euthanasia and physician-assisted suicide



**Theme: preparing and performing EAS.** The data showed that after agreement to undertake EAS, the next difficult topics are the date and time of the procedure and making arrangements for saying farewell. The nature of the farewell varied widely. The preparatory work was always substantial. How to bid farewell to someone who faces a known time and place of death is an unfamiliar emotional task: A careful balance had to be struck between the acceleration imposed by a planned process and the potential of unending postponement because relatives were not ready to say farewell. *Relative 17: 'From that very moment she has been engaged in reinforcing her sons in a very positive way: you are doing well, go on with your studies, you are a beautiful son, I love you so terribly much. She and the children are very close, she was the pivot of the family'.* Many factors influenced the timing of the performance. There were concerns that patients would lose decision-making competence or that serious progression of symptoms would occur, the hope for a natural death, psychological suffering imposed by the burden of the request, availability of high-quality palliative care and the wish to postpone performance. Agreeing the date and time was a negotiation between patients and physicians. Relatives experienced negotiating the timing of the performance as unnatural, preferring to keep out of this process: *Relative 11: 'I thought it very rude. The GP came in and then it was a matter of picking a date, and then there were two possible dates and then three, but the doctor couldn't come on the 12th and then it had to be the 7th or the 14th, and, then the doctor said the 7th is convenient for me, just as if it was like planning a holiday or a week-end, while it was really about ending someone's life'.* Roles altered during the actual EAS procedure. Physicians stepped into their professional role and took control. They typically reassessed the patient's determination before focussing on carrying out EAS. Protocols for informing other professionals and evaluating the performance were available at the hospice and the nursing homes but not in family practice. These protocols were appreciated as they supported the physician's role at a time of high responsibility. Patients, relatives and physicians greatly valued the rituals that accompany EAS: *Relative 2: 'Yes, that was very nice, beautiful stories and poetry and candles, and she did really listen to her husband and made eye contact; yes, that was very beautiful'.*

**Theme: aftercare and closing.** Relatives and physicians were enthusiastic participants in the research interview that took place after EAS. It was an opportunity to reflect on the process. Both parties commented on the burden EAS placed on them and underlined the importance of allowing enough time to pass in order to fully consider the request and its implications. Most relatives and physicians had positive reflections. Relatives also mentioned difficulties accepting what seemed to them a rapid process of decision-making that led to a decision that was often difficult for them to comprehend. Many said that the step of planning a farewell disturbed them, given the usual taboos around talking about death and the convention to always hope that death will be postponed: *Relative 29: 'It was*

*so very difficult for me to let her go, to be so aware of saying farewell, and now I notice that as time passes it gets harder and harder for me*'. Physicians reported feelings of surprise, and of being placed under pressure, when a request was made. Sometimes they felt reluctant to spend the necessary time, to face the emotional drain and to take on the professional responsibility. They admitted developing an aversion towards performance: that EAS was one of the most challenging tasks they ever face and is reluctantly agreed. They reported the need of personal support during this time: *Physician 4: 'I have talked about it with you, with the psychiatrist, and later on I phoned with the elderly care physician and that was very useful for me to make it acceptable*'.

## Discussion

Responding to a request for EAS is reported to be one of the most difficult tasks in medical practice: it brings patients, relatives and physicians together in an intense collaboration of decision-making about how to deal respectfully with Responding to a request for EAS is reported to be one of the most difficult tasks in medical practice: it brings patients, relatives and physicians together in an intense collaboration of decision-making about how to deal respectfully with 'unbearable suffering'.<sup>36;37</sup> Our study provides an overview from daily practice of decision-making in a request for EAS. In studying the complex process, five consecutive phases that can be seen as five key themes could be identified: 1) initiation of sharing views and values about EAS, 2) building relationships as part of the negotiation, 3) fulfilling legal requirements, 4) detailed work of preparing and performing EAS and 5) aftercare and closing.

Our study has some limitations. As a result of the study design, we do not know which patients were not invited or refused to participate and whether this possible exclusion was related to a specific attitude towards EAS or decision-making from the participants' perspective. A second limitation is the fact that the primary researcher conducted all interviews. Its strengths are the unique multi-participants, and the representativeness of the total of 32 cases, varying in diagnoses, demographics, geographic backgrounds, granted and refused requests. The different timings of the interviews within cases, known as serial method, further add to its strengths as it elucidate more aspects of the process in time. In addition, this timing facilitates for close relatives and attending physicians reflecting upon the decision- making process as a whole.

Our unique set of data provides a source of 'learning in reflection'.<sup>24</sup> Making the complex decision is a carefully negotiated, shared process that demands the highest level of sincerity, communication and understanding of family dynamics as well as firm professional behaviour. A two-way information exchange and a profound deliberation stage about choices, options and preferences are crucial for satisfactory

decision-making. The physician and the patient must acknowledge that they both have a say in the outcome. Making decisions about EAS can best be understood as being distributed across time, courses of actions, people and situations.<sup>38;39</sup> Our study underlines that decision-making EAS is a demanding experience for all participants and that patients and relatives greatly value physicians' engagement in open discussions.<sup>40;41</sup> We found, in agreement with earlier research,<sup>42</sup> that talking about the request prepared relatives for the imminent death and facilitated saying farewell. We newly uncovered relatives' reflections about unresolved feelings regarding the speed of the decision-making and the unnaturalness of the performance and that aftercare was not systematically provided.

The main findings of our study leads to the recommendation approach requests for EAS in the framework of shared decision-making (Figure 1). Our study newly adds that a possible request for EAS should be put timely on the agenda to be able to fulfil the requirements of this complex end-of-life decision-making. It is important to initiate a sharing of views and values about end of life and EAS early on in the palliative care trajectory, to build and foster a relationship with patient and relatives; to fulfil legal requirements; to secure a timely, detailed preparation and performing of EAS and to provide aftercare.

Our study has implications for policymakers: considering a request for EAS requires exquisite skills in talking about end of life and in shared decision-making: skills that are neither commonplace nor included in existing curricula. To improve the management of requests for EAS, future research should address the hindrances that physicians encounter in the early communication of end-of-life preferences and the support they need to deal with the requests.

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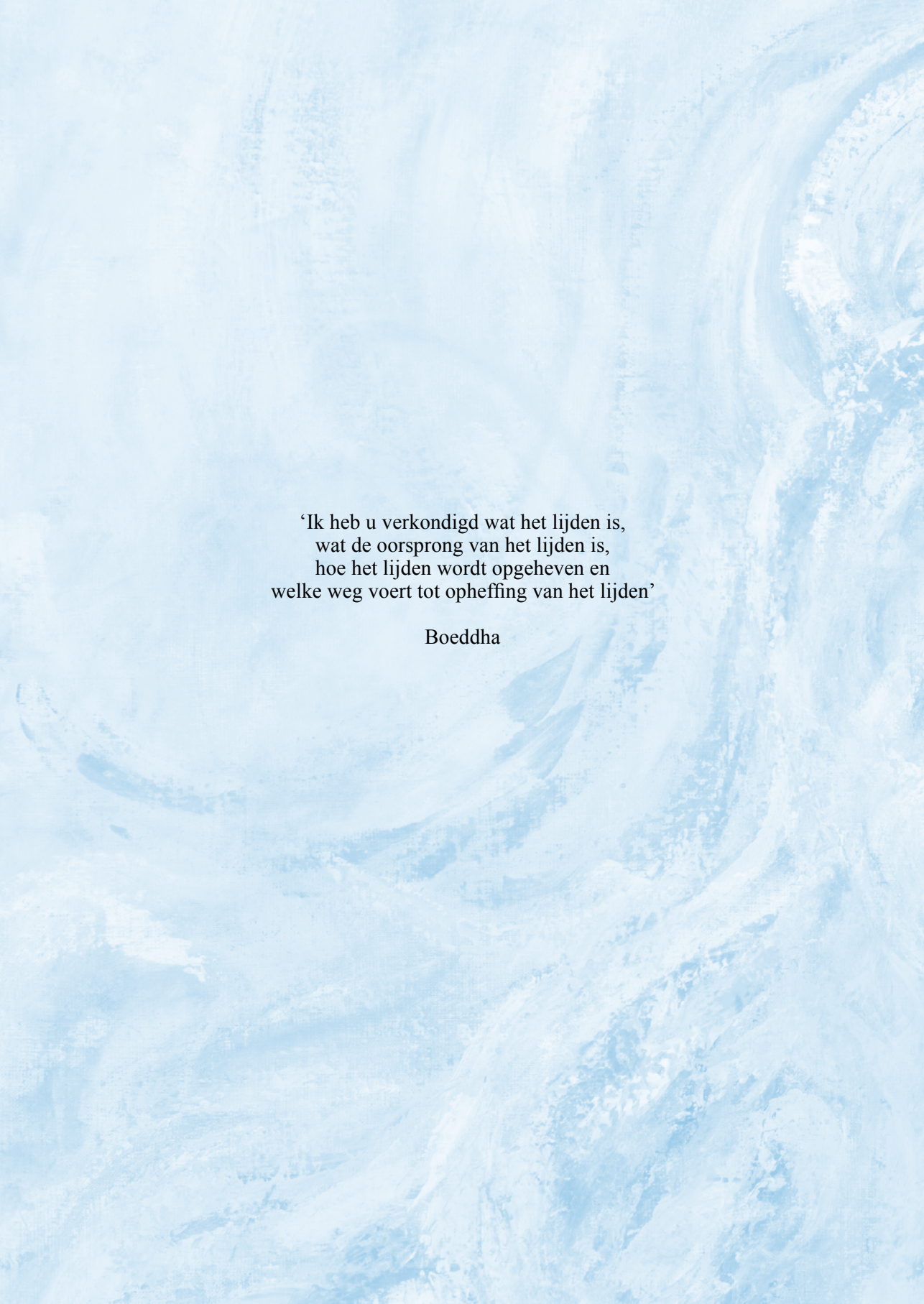
Appendix 1 Characteristics of patients who explicitly requested euthanasia or physician-assisted suicide

Patient number	Gender	Age (years)	Diagnosis	Request	Follow-up (1 year)
1	Female	53	Lung cancer	Honoured	EAS
2	Male	43	Liver cancer	Honoured	EAS
3	Male	88	Colon cancer	Honoured	EAS
4	Male	88	Parkinson disease	Refused	Palliative sedation
5	Male	54	Gastric cancer	Honoured	EAS
6	Female	71	Gall bladder cancer	Honoured	EAS
7	Male	43	Depression	Refused	Treated
8	Female	92	Tired of life	Refused	Alive
9	Female	57	Sigmoid cancer	Honoured	EAS
10	Male	65	Depression	Refused	Treated
11	Female	49	Breast cancer	Honoured	EAS
12	Male	80	Parotid cancer	Refused	Starvation
13	Female	70	Parkinson disease	Honoured	EAS
14	Male	32	Schizophrenia	Refused	Alive
15	Female	65	Breast cancer	Honoured	EAS
16	Female	55	Nasopharyngeal cancer	Honoured	EAS
17	Female	80	Tired of life	Refused	Alive
18	Female	55	Ovarian cancer	Refused	Palliative sedation
19	Female	89	Tired of life	Refused	Alive
20	Female	62	Anxiety disorder	Refused	Alive
21	Male	62	Kidney cancer	Honoured	EAS
22	Male	96	Heart failure	Honoured	EAS
23	Male	83	Lung cancer	Honoured	EAS
24	Female	80	Pain syndrome	Honoured	EAS
25	Male	75	MND	Honoured	EAS
26	Female	77	Pain syndrome	Honoured	EAS
27	Female	94	Tired of life	Refused	Alive
28	Male	77	Bladder cancer	Honoured	EAS
29	Female	65	Pain syndrome	Honoured	EAS
30	Male	61	Alzheimer's disease	Honoured	EAS
31	Male	65	MND	Honoured	EAS
32	Female	76	MND	Honoured	EAS

EAS = euthanasia or physician-assisted suicide    MND = motor neuron disease



Residence	Education level	Occupation	Marital status	Number of children	Religion
Hospice	Intermediate	Administrator	Married	2	-
Hospice	High	Teacher	Single	0	Humanist
Hospice	Intermediate	Director	Widower	2	-
Nursing home	Basic	Farmer	Married	7	Catholic
Home	High	Manager	Married	2	-
Home	Basic	Housewife	Widow	3	-
Home	High	None	Single	0	Buddhist
Home	Intermediate	Administrator	Widow	0	-
Home	High	Lawyer	Divorced	2	-
Home	High	Director	Divorced	2	-
Home	High	Manager	Married	2	-
Home	High	Teacher	Widower	2	Agnostic
Home	High	Teacher	Married	2	Humanist
Home	Basic	None	Single	0	-
Home	Intermediate	Home care	Divorced	2	There is more
Home	Intermediate	Accountant	Married	3	Protestant
Home	Intermediate	Café owner	Widow	3	My own
Hospital	Intermediate	Secretary	Married	3	-
Home	Intermediate	Nun	Single	0	-
Home	Basic	Author	Single	0	Atheist
Home	High	Manager	Married	0	Secular
Home	Basic	Farmer	Widower	1	-
Home	High	Businessman	Married	4	-
Nursing home	Basic	Housewife	Married	4	-
Home	Basic	Manager	Married	5	
Home	High	Psychotherapist	Widow	3	Humanist
Home	Basic	Housewife	Widow	1	Catholic
Home	Intermediate	Salesman	Married	2	-
Hospice	Low	Housewife	Widowed	2	-
Home	High	Director	Married	2	-
Home	Intermediate	Estate agent	Married	3	Catholic
Hospice	Intermediate	Housewife	Widow	2	Protestant



‘Ik heb u verkondigd wat het lijden is,  
wat de oorsprong van het lijden is,  
hoe het lijden wordt opgeheven en  
welke weg voert tot opheffing van het lijden’

Boeddha



# *Chapter 5*

Exploring unbearable suffering in a request for euthanasia.  
A comparison of perspectives of patients, relatives,  
attending physicians and independent doctors

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## Abstract

**Background** Unbearable suffering is a major condition for lawful euthanasia in the Netherlands. The law provides no definition of unbearable suffering. It is an ambiguous concept; the specific circumstances of every individual case must be considered to interpret it. The aim of the study was to better understand the perceptions of unbearable suffering of patients, physicians, relatives, and independent doctors in cases where the patient and the attending physician agree about unbearable suffering.

**Methods** We completed a secondary analysis of transcripts of in-depth interviews with patients explicitly requesting euthanasia or assistance in dying, their most involved relatives, and the attending physicians. We also included reports from independent doctors among the 80 transcripts.

**Results** We distinguished between medical, psycho-emotional, social-environmental, and existential themes. There is a substantial resemblance of the patients' existential, medical, and psycho-emotional themes to those of the other participants. Relatives reflected the views of the patients in all the themes, and strikingly so in the existential theme. The attending physicians and independent doctors had little affinity with the elements of the socio-environmental theme and especially the elements 'being a burden' and 'prospect of going to a nursing home'. Independent doctors scarcely reported 'nothing left to live for' to the Regional Review Committees.

**Conclusions** The constituent elements of patient's suffering include medical, psycho-emotional, socio-environmental, and existential themes. We hypothesize that, if attending physicians and independent doctors systematically explore these elements and report them to the Regional Review Committees, the knowledge and understanding of the patient's unbearable suffering will improve.

## Background

In states and countries where euthanasia or physician-assisted suicide (EAS) has been legalized – Oregon, Washington State, Montana, Switzerland, Belgium, Luxembourg, and the Netherlands – unbearable suffering is a major condition in the professional assessment for granting a request for EAS.<sup>1-4</sup> In the Netherlands, EAS is deemed legal if the six rules of due care are adhered to (Box 1). The second rule of due care, established in the Dutch Euthanasia Act<sup>5</sup>, states that the attending physician must be convinced that the patient requesting EAS is in a situation of

‘unbearable and hopeless suffering’.<sup>6,7</sup> The understanding of unbearable suffering is also required to adhere to the fourth rule of due care, which requires the patient and the attending physician to be convinced that there is no other reasonable solution for the situation. The euthanasia law itself provides no definition of unbearable suffering. It is an ambiguous concept, and to interpret it, one must carefully consider the specific circumstances of each individual case. The first interpretations of unbearable suffering came from case law.<sup>8,9</sup> The evaluation of the Euthanasia Act<sup>10</sup> made it clear that, according to physicians, agreement about what is ‘unbearable’ was most difficult to achieve in daily practice. Buiting and colleagues reported that 25% of the physicians had problems assessing unbearable suffering.<sup>11</sup> Severely ill patients with limited life expectancy usually have little discussion with the physician about suffering being unbearable.<sup>12,13</sup> However, in cases of early dementia and existential suffering, patients and physicians often differ in their views.<sup>14</sup> Attending physicians have a narrower view of unbearable suffering.<sup>15</sup>

The assessment of unbearable suffering is also a major consideration in the independent consultation, usually with a Support and Consultation for Euthanasia in the Netherlands (SCEN) specialist, as legally required for lawful euthanasia. The report of the independent doctor is one of the documents with which the Regional Review Committees (RRCs) form their opinion about the fulfillment of the rules of due care. Earlier research shows that SCEN specialists have a narrower view of suffering than the RRCs; the emphasis in their reports is on physical aspects.<sup>16</sup> Research also gives evidence that if non-physical aspects of suffering was the core of a euthanasia request, there was variance between and within groups of physicians, SCEN specialists, and members of the RRCs in their judgment of the patient’s suffering.<sup>17</sup> The SCEN specialists were most restrictive, and the RRCs had the most liberal view. Unbearable suffering was a major consideration in the RRCs’ assessments<sup>16</sup>, and their annual reports provide growing evidence about the interpretation and constituent elements of unbearable suffering.<sup>18</sup>

There is, however, no current knowledge of the perspectives of the unbearable suffering of the patient, the close relative, the attending physician, and the independent doctor who are involved in an explicit request for euthanasia in a particular case. The first aim of this study was to obtain in-depth information about the perspectives of patients, close relatives, and attending physicians on constituent elements of unbearable suffering in cases where the patient and physician agree about unbearable suffering and performance. The second aim was to compare the perspectives of these participants and gain insight into which elements independent doctors report to the RRCs.

*Definition.* A State Committee installed by the Health Council in the Netherlands in 1985 defined euthanasia as “the intentional termination of life by someone other than the person concerned at his or her request” and assisted suicide as

“intentionally assisting in a suicide of another person or procuring for that other person the means”.<sup>19</sup> Neither is an offence if committed by a physician who fulfills the rules of due care set out in Article 293 of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act.<sup>5</sup>

#### Box 1. Criteria for euthanasia or physician-assisted suicide

Euthanasia or physician-assisted suicide has been legal in the Netherlands since 2002, provided that the six criteria for due care of Article 293, paragraph 2, of the Dutch Penal Code<sup>5</sup> are met.

The treating physician must:

- a. Be convinced that the patient's request is voluntary and well-considered
- b. Be convinced that the patient's suffering is unbearable and hopeless
- c. Inform the patient about his/her situation and prospects
- d. Be convinced, as the patient must also be, that there is no other reasonable solution for his/her situation
- e. Consult at least one other independent doctor, who must see the patient and give his/her written opinion about whether the first four criteria have been satisfied
- f. Use all due care in terminating the life or assisting in the suicide

## Methods

### Study Design

We performed a secondary analysis of the data that were originally collected from in-depth interviews with patients with an explicit request for EAS, their most-involved relatives and their attending physicians.<sup>20,21</sup> These patients and participants were recruited in following several selection pathways. We worked with the network of Support and Consultation on Euthanasia in the Netherlands (SCEN). We also contacted a hospice, a hospital, and a nursing home and placed a notice in the journal *Right to die – NL*, inviting patients to contact us if they wished to participate in the study. The original interviews took place between April 2008 and July 2009 and were conducted as follows: 31 with patients, 31 with relatives and 28 with GPs. In addition we retrieved 24 written reports of consulted independent physicians. The requests of 11 cases were not granted. In four cases the patients reported ‘being tired of life’ which is ruled out as a basis for EAS by the Dutch Supreme Court.<sup>22</sup> In four cases a psychiatric disorder was the cause of the patients’ suffering. Such requests are seldom granted whereas physicians struggle by the death wish being driven by the disorder and with the possibility of recovery.<sup>23</sup> The other refusals were due to a difference of opinion about ‘unbearable suffering’, doubt about decision-making competence, and the policy of the residential setting. To gain insight information about the extent to which relative, attending physician and consultant know the constituent elements of unbearable suffering of the patient we selected the cases in which the patient and the attending physician agreed about unbearable suffering and EAS was granted. “Secondary analysis” is an established approach among qualitative researchers to generate new knowledge in the discipline of healthcare.<sup>24–26</sup>



The local research ethics committee approved the original study. All participants gave their informed consent. Patients with an explicit request for EAS were interviewed in the same period in which the independent consultation took place. The relatives and the physician were interviewed approximately 4 weeks after the patient's death. All interviews were audio-recorded and transcribed verbatim. Demographics were collected before the interviews; medical records and consultation reports, afterwards. The perspectives of the independent doctors were extracted from their reports to the RRC.

### **Interviews**

The original interviews were planned on location and lasted 30 to 120 min. When possible, patients were interviewed alone to ensure they felt free to voice their own views. An experienced female physician and SCEN specialist (MD), not in any way involved in the care for the requesting patient, conducted the interviews. Given the possible sensitivity of the topics, there were no preset questions. The topic guide aimed to explore the suffering of patients with an explicit request for EAS, to understand each patient's unbearable suffering, and to explore the perspectives of the closest relative and the physician on the patient's suffering.<sup>20,21</sup>

### **Data Analysis**

We used ATLAS.ti version 5.5 to complete the secondary, thematic analysis of the interview data and the written reports of the independent doctors. We used the codes, categories, and themes that emerged from our original analysis of the constituent elements of the patients' suffering as a code book (Appendix 1).<sup>20</sup> New codes could be added. We used the quotations about unbearable suffering, coded independently by two researchers (M.D and M.S), for analyzing the decision-making of participant clusters (patient, relative, physician, and independent doctor).<sup>21</sup> M.D reanalyzed all transcripts thematically to better understand the elements that each individual participant attributed to unbearable suffering. We used SPSS to compare these elements within cases.

## **Results**

In 20 of the 32 cases included in the original study<sup>20</sup>, the patient and the physician agreed about unbearable suffering, and the request was granted and performed (Appendix 2). We analyzed 80 transcripts; 20 interviews each with patients, relatives, and attending physicians; and 20 written reports from consulted independent doctors.

### **Participant Characteristics**

The 20 patients were 43–88 years old (median: 65 years). Eleven were women. Twelve were diagnosed with cancer; five, with a degenerative neurological disease; and three had chronic pain syndrome. The relatives, aged 26–78 (median 53) were



the patients' wives (7), daughters (6), husbands (4), sons (2), and sister (1). The 20 attending physicians were 28–62 years old (median: 53 years). Sixteen were men. Seventeen were GPs, two were elderly-care physicians, and one was a physician trainee. Three physicians and both elderly-care physicians were also SCEN-specialist. Their experience varied widely from having assisted 1–20 EAS. The 20 independent doctors were 46–61 years old (median: 57 years), 19 were SCEN-specialists and 15 were men. Eleven were GPs, six were specialists in the care of the elderly, two were intensivists, and one had no specialization. Their experience varied from 1 to 12 cases of EAS annually (Table 1).

Table 1 Participant characteristics in cases where EAS was granted

Patient characteristics				
Gender	Diagnoses (number)		Age in years	
9 Male	Cancer (6) Degenerative neurological disease (3)		43 – 88 ( median 65)	
11 Female	Cancer (6) Degenerative neurological disease (2) Pain syndrome (3)		49 – 80 ( median 65)	
Physician characteristics				
Gender	Specialization	SCEN	Age in years	Experience of EAS
16 Men	16 Physicians	3	37 – 62	1 (in 4 years) – 20 (in 24 years)
4 Female	1 Physician 1 Physician trainee 2 Care of the elderly	1  2	28 – 60	1 (the first) – 6 (in 19 years)
Relative characteristics				
Gender	Relation		Age in years	Care in hours a day
6 Male	4 Husband 2 Son		52 – 77 31 – 50	2 – 24 1 – 2
14 Female	7 Wife 1 Sister 6 Daughter		49 – 78 31 26 – 52	24 4 – 8 1 – 6
Independent doctor characteristics				
Gender	Specialization		Age in years	Consultations a year
16 Male	11 Physician* 2 Anesthesiology 2 Care of the elderly 1 No specialization		49 – 61	1* - 12
4 Female	2 Physician 2 Care of the elderly		47 – 53	5 - 8

\*Was not a SCEN specialist EAS = Euthanasia or physician-assisted suicide

### Comparison Constituent Elements Unbearable Suffering

Table 2 shows that within the medical theme as a whole, agreement with the patients was similar: independent doctors, 73%; relatives, 70%; and attending physicians, 69%. Additionally within this same theme approximately 30 % of the medical elements named by attending physician, relative and independent consultant were unreported by the patient. Within the psycho-emotional theme, the relatives agreed with the patients about 71% of the elements; the attending physicians about 68%; and the independent doctors, about 66%. Within this theme about 20 % of the medical elements named by attending physician, relative and independent doctors were unreported by the patient. Within the socio-environmental theme the relatives' views correlated with the patients' in 53% of the cases; the attending physicians in 50%, and the independent doctors in 30%. Within this theme about 15 % of the elements named by attending physician and the independent doctors were unreported by the patient. The relatives named 20 % socio-environmental elements that were unreported by the patient. Within the existential theme as a whole, the relatives agreed with the patient to the extent of 91%; the independent doctors, 75%; and the attending physicians, 71%. In this theme only 10% of the elements named by the relatives, the attending physicians and the independent doctors were unreported by the patient.

Table 2 Agreement of constituent elements of unbearable suffering per theme as named by patients compared with respectively physician, consultant and relative in %

	Participant	Mentioned by patient and ...	Mentioned by ... and not by patient
Medical	Physician	69	32
	Consultant	73	27
	Relative	70	23
Psycho-emotional	Physician	68	18
	Consultant	66	16
	Relative	71	23
Socio-environmental	Physician	50	13
	Consultant	30	14
	Relative	53	22
Existential	Physician	71	10
	Consultant	75	10
	Relative	91	10

### Medical Theme

Table 3 and 4 shows that progression of the illness, exhaustion, physical decline, cognitive decline, and pain are among the most mentioned elements in the medical theme. Casus 7, concerning a 70 years old married woman diagnosed with M. Parkinson, interviewed 164 days before the performance of euthanasia, gives a illustrative example of a high agreement in reported elements and a lack of elements that were named by only one participant. Cognitive decline, problems with the urine and faeces, progression of the illness and equilibrium dysfunction

were reported by patient, relative, GP and SCEN-specialist. The physical decline was only mentioned by the two physicians. Choking was not mentioned by the relative. This narrative is characterized by a long and intensive trajectory. The first conversation about a possible EAS between the patient and the GP took place more than two years before the performance. The evolution of unbearable suffering was a recurrent topic during the home visits of the GP. The early interview (164 days before performance) and the differences in timing of the interview seem not to affect the reported elements. Casus 3, an 88 years old man diagnosed with colon carcinoma, euthanasia was performed one day after the interview, gives a good example of a low agreement in elements within the medical theme. Loss of appetite was the only element with a 100% agreement involved participants. The patient was the only one who reported treatment complications, while decline was named by the other three, cachexia and exhaustion by the two physicians and progression of the illness solely by the GP. This patient requested euthanasia the day after being transferred from hospital to hospice. The GP felt overwhelmed by the request and to some extent pressurized by the determination of the patient towards the timing of the performance.

### **Psycho-emotional Theme**

Table 3 and 4 show that loss of autonomy, dependency, loss of self, fear of cognitive decline, being worn out, fear of loss of control, and negative feelings are among the most mentioned elements within the psycho-emotional theme. Casus 2, a 43 years old man diagnosed with liver cancer, dying 12 days after the interview, gives an illustrative example of the agreement of elements within the psycho-emotional theme. Patient, relative, GP and SCEN-specialist all reported loss of autonomy and loss of self. The GP did not mention being worn out and the SCEN-specialist did not name dependency in difference with the other involved. Casus 8, a 65 year old woman, diagnosed with breast cancer, interviewed 29 days before death, in the contrary gives a rare example of a differences in mentioned psycho-emotional elements. She named dependency, loss of autonomy, and fear for loss of control and fear for cognitive and physical decline. Her son and male GP named only loss of autonomy and fear for loss of control. The independent doctors, the only non SCEN-specialist, mentioned no psycho-emotional element at all.

### **Socio-environmental Theme**

Table 3 and 4 show that six or more patient named being a burden, isolation, the prospect of living in a nursing home, and communicative problems in the socio-environmental theme. Casus 17, a 65 years old man diagnosed with Motor Neuron Disease, dying 86 days after being interviewed, illustrates the non-reporting of prospect of a nursing home and being a burden by both the attending physicians and SCEN-specialists. It also exemplifies the variance between patient, relative and GP with regard to communicative problems and isolation.

## Existential Theme

Table 3 and 4 shows that all 20 patients, attending physicians and independent doctors named hopelessness. Only two relatives did not mention hopelessness. Case 10, a 83 years old man, diagnosed with lung cancer, dying 10 days after the interview, exemplifies the resemblance in reported elements within this theme. The patient naming hopelessness, being ready with life loss of quality of life and pointlessness; the relative not naming hopelessness; the GP only mentioning hopelessness and the SCEN-specialist not mentioning being ready with life.

Table 3. Numbers of participants naming element and agreement between patient and participant within cases

	Patient	Physician	Consultant	Relative
<b>Medical elements: agreement</b>		<b>69%</b>	<b>73%</b>	<b>70%</b>
Progression of the illness	13	13	13	14
Tiredness and exhaustion	10	8	9	9
Physical decline	7	7	6	7
Cognitive decline	7	6	7	7
Pain	6	7	8	5
Problems with urine and/or feces	3	4	2	3
Nausea and/or vomiting	3	3	3	3
Treatment complications	3	1	0	1
Dyspnea	2	3	3	1
Loss of appetite	2	2	3	3
Resuscitation; tube feeding	2	2	2	2
Equilibrium not functioning	2	1	2	1
Choking	1	1	1	0
Swallowing problems	1	3	2	2
Depression	1	1	1	1
Side effects of palliative treatment	1	0	1	0
Cachexia	0	3	2	0
<b>Psycho-emotional elements: agreement</b>		<b>68%</b>	<b>66%</b>	<b>71%</b>
Loss of autonomy	16	16	11	14
Dependency	15	12	12	11
Loss of self	11	7	9	11
Fear of cognitive decline	10	5	7	6
Being worn out	8	6	8	10
Fear of loss of control	8	9	7	10
Negative feelings	7	7	4	6
Fear of future suffering	7	7	6	7
Fear of physical decline	3	0	0	0
Fear of loss of dignity	2	1	1	2
Fear of pain	1	0	0	1
Fear of choking to death	1	2	2	1
Loss of dignity	1	2	2	3

<b>Socio-environmental elements: agreement</b>		<b>50%</b>	<b>30%</b>	<b>53%</b>
Being a burden	13	6	3	10
Loneliness: isolation	8	5	4	6
Prospect of a nursing home	7	1	1	4
Communicative problems	6	6	3	5
Loneliness: loss of a loved one	3	3	2	2
Discontent about residence and/or care	2	0	0	0
<b>Existential elements: agreement</b>		<b>71%</b>	<b>74%</b>	<b>90%</b>
Hopelessness	20	20	20	18
Loss of important and pleasurable things, quality of life	18	11	14	19
Pointlessness, loss of purpose in life	17	11	16	16
Life is over, being ready with life	10	10	4	13

Table 4 The perceptions of patients, relatives, physicians and consultants on constituent elements of patient's unbearable suffering

	Theme	Category	Patients	Relatives	Physicians	Consultants
Causus 1	Medical	Problems urine and/or faeces; incontinence	x		x	x
		Side effects palliative treatment	x			x
		Progression of the illness		x		
		Pain			x	x
		Dyspnoea			x	x
		Tiredness; exhaustion				x
	Psycho-emotional	Loss of autonomy	x	x	x	x
		Fear for cognitive decline	x	x	x	x
		Loss of dignity	x	x	x	x
		Loss of self	x	x		x
		Dependency	x	x		x
		Being worn out		x		
		Fear for suffering		x		
		Negative feelings		x		
	Socio-environmental	Loneliness: isolation		x		
		Being a burden			x	x
	Existential	Hopelessness	x		x	x
		Loss of important and pleasurable things "not being able anymore"; Loss of quality of life;	x			
		Loss of joy				
		Pointlessness	x	x	x	x
		Being ready with life		x	x	
Causus 2	Medical	Tiredness; exhaustion	x	x	x	x
		Dyspnoea	x			
		Physical decline		x		x
		Progression of the illness		x		
	Psycho-emotional	Loss of autonomy	x	x	x	x
		Loss of self	x	x	x	x
		Dependency	x	x	x	
		Being worn out	x	x		x
	Socio-environmental	Being a burden	x	x		
	Existential	Hopelessness	x	x	x	x
		Loss of important and pleasurable things "not being able anymore"; Loss of quality of life;	x	x		
		Loss of joy of life				
		Pointlessness	x	x	x	
		Being ready with life	x	x	x	

	Theme	Category	Patients	Relatives	Physicians	Consultants
Casus 3	Medical	Treatment complications	x			
		Loss of appetite	x	x	x	x
		Physical decline		x	x	x
		Cachexia			x	x
		Tiredness; exhaustion			x	x
		Progression of the illness			x	
	Psycho-emotional	Loss of autonomy	x	x	x	x
		Loss of self		x	x	
		Fear for suffering		x		
		Loss of dignity		x		x
		Dependency			x	x
	Socio-environmental	Loneliness: loss of a loved one	x		x	
		Being a burden		x		
	Existential	Hopelessness	x	x	x	x
		Loss of important and pleasurable things “not being able anymore”; Loss of quality of life;	x	x	x	x
		Loss of joy				
		Pointlessness	x	x	x	x
Casus 4	Medical	Physical decline	x			
		Nausea; vomiting	x		x	x
		Progression of the illness	x			x
		Cachexia			x	
		Tiredness; exhaustion			x	x
	Psycho-emotional	Loss of autonomy	x	x	x	
		Negative feelings	x		x	
		Fear for loss of dignity	x	x	x	x
		Fear for suffering	x		x	x
		Fear for cognitive decline		x	x	
	Socio-environmental	Being a burden	x	x	x	
	Existential	Hopelessness	x	x	x	x
		Loss of important and pleasurable things “not being able anymore”; Loss of quality of life;				x
		Loss of joy				
		Being ready with life	x	x		
		Pointlessness		x		x



	Theme	Category	Patients	Relatives	Physicians	Consultants
Causus 5	Medical	Complications medical treatment	x			
		Pain	x	x		
		Nausea; vomiting	x	x	x	x
		Progression of the illness	x	x	x	
		Tiredness; exhaustion	x	x	x	x
		Physical decline			x	
	Psycho-emotional	Loss of self	x	x		x
		Dependency	x	x	x	x
		Negative feelings: depressed mode, fear, bitterness, disappointment	x	x	x	x
		Fear for cognitive decline	x	x		x
		Loss of autonomy	x	x	x	
		Fear for suffering			x	x
		Fear for loss of control			x	
	Socio-environmental	Being a burden	x	x		x
		Discontent about residences and care	x			
		Loneliness: isolation	x	x	x	x
		Loneliness: lose of a loved one	x	x	x	x
	Existential	Hopelessness	x	x	x	x
		Being ready with life	x	x	x	x
		Loss of important and pleasurable things “not being able anymore”; Loss of quality of life; Loss of joy	x	x		
		Pointlessness	x	x	x	x
Causus 6	Medical	Complications medical treatment	x	x	x	
		Dyspnoea	x			
		Tiredness; exhaustion	x	x		x
		Nausea; vomiting	x	x	x	
		Pain	x		x	x
		Progression of the illness	x			x
		Cognitive decline		x		x
	Psycho-emotional	Loss of self	x	x	x	x
		Negative feelings: sadness, fear	x	x		x
		Fear for suffering	x	x	x	x
		Fear for pain	x	x		
		Loss of autonomy	x		x	x
		Being worn out		x		x
		Fear for loss of control		x	x	x
	Socio-environmental					
	Existential	Hopelessness	x	x	x	x
		Being ready with life	x	x		
		Loss of important and pleasurable things “not being able anymore”; Loss of quality of life; Loss of joy	x	x	x	x
		Pointlessness	x	x		x

	Theme	Category	Patients	Relatives	Physicians	Consultants
Casus 7	Medical	Cognitive decline	x	x	x	x
		Problems urine and/or faeces; incontinence	x	x	x	x
		Progression of the illness	x	x	x	x
		Choking	x		x	x
		Equilibrium not functioning	x	x	x	x
		Physical decline			x	x
	Psycho-emotional	Loss of self	x	x	x	
		Dependency	x	x	x	x
		Fear for suffering	x		x	
		Negative feelings: emptiness, shame	x		x	x
		Loss of autonomy			x	
	Socio-environmental	Loneliness: Isolation	x		x	x
		Inability to participate in conversations	x	x	x	x
		Being a burden		x		
		Prospect of a nursing home	x			
		Loss of social significance			x	
	Existential	Hopelessness	x	x	x	x
		Being ready with life	x	x	x	
		Loss of important and pleasurable things “not being able anymore”; Loss of quality of life;	x	x	x	x
		Loss of joy				
Casus 8	Medical	Cognitive decline	x	x	x	x
		Progression of the illness	x		x	x
		Dyspnoea			x	
	Psycho-emotional	Dependency	x			
		Fear for cognitive decline	x			
		Fear for physical decline	x			
		Fear for loss of control	x	x	x	
		Loss of autonomy	x	x	x	
	Socio-environmental	Being a burden	x			
		Prospect of a nursing home	x	x		
		Communication problems	x		x	
	Existential	Hopelessness	x		x	x
		Loss of important and pleasurable things “not being able anymore”; Loss of quality of life;		x		
		Loss of joy				
		Pointlessness				x

	Theme	Category	Patients	Relatives	Physicians	Consultants
Causus 9	Medical	Physical decline	x	x	x	x
		Tiredness, exhaustion	x	x	x	
		Pain	x	x		x
		Loss of appetite		x	x	x
		Progression of the illness		x	x	x
		Cachexia			x	x
	Psycho-emotional	Loss of self	x	x		x
		Being worn out	x	x	x	x
		Dependency	x	x	x	
		Fear for cognitive decline	x			
		Fear for physical decline	x			
		Loss of autonomy	x	x	x	x
		Loss of control		x	x	x
		Negative feelings: Impotence		x		
	Socio-environmental	Being a burden	x		x	
		Loneliness: isolation	x	x		
	Existential	Hopelessness	x	x	x	x
		Loss of quality of life	x	x	x	
		Being ready with life	x	x	x	
		Loss of important and pleasurable things “not being able anymore”; Loss of quality of life; Loss of joy	x	x	x	x
		Pointlessness	x	x	x	x
Causus 10	Medical	Cognitive decline	x	x		
		Loss of appetite	x	x		x
		Progression of the illness	x	x		x
		Tiredness; exhaustion	x	x		
		Dyspnoea		x	x	x
	Psycho-emotional	Fear for cognitive decline	x			x
		Fear for loss of control	x	x	x	
		Loss of autonomy	x	x	x	x
		Fear for choking			x	x
	Socio-environmental	Being a burden		x	x	
		Prospect of a nursing home		x		
	Existential	Hopelessness	x		x	x
		Being ready with life	x	x		
		Loss of important and pleasurable things “not being able anymore”; Loss of quality of life; Loss of joy	x	x		x
		Pointlessness	x	x		x

	Theme	Category	Patients	Relatives	Physicians	Consultants
Causus 11	Medical	Physical decline	x			
		Pain	x	x	x	x
		Progression of the illness	x	x	x	x
	Psycho-emotional	Being worn out	x			
		Dependency	x		x	x
		Isolation	x			
	Socio-environmental	Discontent about residence and/or care	x			
		Hopelessness	x	x	x	x
	Existential	Loss of important and pleasurable things “not being able anymore”; Loss of quality of life; Loss of joy	x	x	x	x
		Pointlessness	x			
Causus 12	Medical	Resuscitation and/or tube feeding	x	x	x	x
		Progression of the illness	x	x		x
		Pain				x
	Psycho-emotional	Dependency	x	x	x	x
		Fear for cognitive decline	x	x	x	x
		Fear for suffering	x	x	x	x
		Fear for loss of control	x	x		
		Loss of autonomy	x	x	x	x
		Being worn out		x		x
	Socio-environmental	Being a burden	x			
		Communicative problems	x	x	x	x
		Prospect of a nursing home	x	x	x	x
	Existential	Hopelessness	x	x	x	x
		Pointlessness	x	x		x
		Being ready with life		x	x	
		Loss of important and pleasurable things “not being able anymore”; Loss of quality of life; Loss of joy		x	x	x

	Theme	Category	Patients	Relatives	Physicians	Consultants
Causus 13	Medical	Physical decline	x	x	x	x
		Pain	x	x	x	x
		Tiredness; exhaustion	x	x	x	
		Depression	x	x	x	x
		Equilibrium not functioning	x			x
		Progression of the illness		x	x	
	Psycho-emotional	Loss of self	x			x
		Being worn out	x	x	x	
		Dependency	x		x	x
		Negative feelings: depressed mode, life is a harassment	x	x	x	
	Socio-environmental	Being a burden,	x			
		Loneliness: isolation	x	x	x	x
		loneliness: loss of a loved one	x	x	x	x
	Existential	Hopelessness	x	x	x	x
		Being ready with life	x	x	x	x
		Loss of important and pleasurable things “not being able anymore”; Loss of quality of life;	x	x	x	x
		Loss of joy of life				
		Pointlessness	x	x	x	x
Causus 14	Medical	Physical decline	x	x	x	x
		Progression of the illness	x		x	x
		Tiredness; exhaustion	x	x	x	x
	Psycho-emotional	Being worn out	x	x	x	x
		Fear for cognitive decline	x			x
		Fear for loss of control	x	x	x	x
		Loss of autonomy	x	x	x	x
		Dependency		x		
	Socio-environmental	Being a burden	x	x		
	Existential	Hopelessness	x	x	x	x
		Being ready with life	x		x	x
		Loss of important and pleasurable things “not being able anymore”; Loss of quality of life;	x	x		x
		Loss of joy of life				
		Pointlessness	x	x	x	x

	Theme	Category	Patients	Relatives	Physicians	Consultants
Casus 15	Medical	Physical decline	x	x	x	x
		Pain	x	x	x	x
		Tiredness; exhaustion	x	x		
		Progression of the illness		x	x	
		Problems urine and faeces; incontinence		x		
	Psycho-emotional	Being worn out	x	x	x	x
		Dependency	x			x
		Fear for decline	x			
		Fear for suffering	x	x		x
		Fear for loss of control		x		
		Loss of self		x		
		Negative feelings: disappointment			x	
	Socio-environmental	Being a burden	x			
	Existential	Hopelessness	x	x	x	x
		Being ready with life	x	x		
		Loss of important and pleasurable things “not being able anymore”; Loss of quality of life;	x	x		
		Loss of joy of life				
		Pointlessness	x	x	x	x
Casus 16	Medical	Cognitive decline	x	x	x	x
		Progression of the illness	x	x	x	x
	Psycho-emotional	Loss of self	x	x	x	x
		Dependency	x	x	x	x
		Fear for suffering	x	x	x	x
		Fear for loss of control	x	x	x	x
		Fear for loss of dignity	x	x		
		Loss of autonomy	x	x	x	x
		Being worn out				x
	Socio-environmental	Being a burden	x		x	x
		Prospect of a nursing home	x	x		
		Isolation				x
	Existential	Hopelessness	x	x	x	x
		Loss of important and pleasurable things “not being able anymore”; Loss of quality of life;	x	x	x	x
		Loss of joy of life				
		Pointlessness	x	x	x	x

	Theme	Category	Patients	Relatives	Physicians	Consultants
Causus 17	Medical	Physical decline	x	x	x	
		Progression of the illness	x	x	x	x
		Swallowing problems			x	x
		Pain			x	
	Psycho-emotional	Loss of self	x		x	x
		Dependency	x		x	
		Fear for loss of control	x			x
		Loss of autonomy	x		x	
		Negative feelings: shame, sadness	x		x	x
		Being worn out		x	x	x
		Fear for suffering	x	x	x	x
	Socio-environmental	Communicative problems	x	x	x	
		Loneliness: isolation	x	x	x	
		Prospect of a nursing home	x			
		Being a burden	x	x		
	Existential	Hopelessness	x	x	x	x
		Loss of important and pleasurable things “not being able anymore”; Loss of quality of life;	x	x	x	x
		Loss of joy of life				
		Pointlessness	x	x	x	x
		Being ready with life		x		
Causus 18	Medical	Tube feeding	x	x	x	x
		Cognitive decline	x		x	x
		Problems urine and faeces; incontinence	x		x	
		Progression of the illness	x	x	x	x
		Tiredness; exhaustion	x		x	x
		Swallowing problems	x	x	x	x
	Psycho-emotional	Being worn out	x	x	x	
		Dependency	x	x	x	x
		Loss of autonomy	x	x	x	x
		Sadness	x			
		Fear for suffering		x		x
		Loss of dignity			x	
	Socio-environmental	Being a burden	x			
		Communicative problems	x	x	x	x
		Isolation	x	x	x	
	Existential	Hopelessness	x	x	x	x
		Loss of important and pleasurable things “not being able anymore”; Loss of quality of life;	x	x	x	
		Loss of joy of life				
		Pointlessness	x	x	x	x



	Theme	Category	Patients	Relatives	Physicians	Consultants
Casus 19	Medical	Cognitive decline	x	x	x	x
		Tiredness; exhaustion	x	x		x
		Nausea; vomiting		x		x
		Physical decline		x	x	
	Psycho-emotional	Fear for loss of control	x	x	x	x
		Loss of self	x	x	x	x
		Being worn out	x			
		Dependency	x	x	x	x
		Fear for cognitive decline	x	x	x	x
		Loss of autonomy	x	x	x	x
		Negative feelings: fear, shame		x	x	
		Prospect of a nursing home	x			
		Being a burden	x	x	x	
	Socio-environmental	Loneliness: isolation	x			
		Existential				
	Existential	Hopelessness	x	x	x	x
		Loss of important and pleasurable things “not being able anymore”; Loss of quality of life; Loss of joy of life	x	x		x
		Pointlessness	x	x		x
		Being ready with life		x	x	
Casus 20	Medical	Cognitive decline	x	x	x	x
		Progression of the illness	x	x	x	x
		Swallowing problems		x	x	
		Problems urine and faeces; incontinence		x	x	
		Pain			x	
	Psycho-emotional	Loss of self	x	x		
		Dependency	x	x		x
		Fear for cognitive decline	x	x	x	x
		Fear for loss of control	x	x	x	x
		Loss of autonomy	x	x		
		Loss of dignity		x		
	Socio-environmental	Prospect of a nursing home	x			
		Communicative problems	x	x	x	
		Being a burden		x		
	Existential	Hopelessness	x	x	x	x
		Loss of important and pleasurable things “not being able anymore”; Loss of quality of life; Loss of joy of life	x	x		
		Pointlessness	x			
		Being ready with life				x

## Discussion

This study shows that it is possible to achieve multi-perspective insight into information about patients' perspectives on unbearable suffering regarding explicit requests for EAS in which there is agreement about unbearable suffering and performance of EAS. Although patients, closest relatives, attending physicians, and independent doctors agreed about suffering being unbearable, they interpreted unbearable suffering in various ways. There is a substantial similarity between patients on the one hand and attending physicians and independent doctors on the other hand regarding the medical, psycho-emotional, and emotional themes. However, views within the socio-environmental theme showed little similarity when we compared patient views with those of attending physicians and independent doctors, especially regarding the elements of 'being a burden' and 'the prospect of going to a nursing home'. Furthermore, independent doctors scarcely reported 'nothing left to live for' to the RRCs. We found evidence that relatives are the ones with views most similar to those of patients in all the themes, and the similarity is striking in the existential theme.

Our study confirms the earlier research of Pasman and colleagues<sup>15</sup>, who report that attending physicians seem to have a narrower perspective on unbearable suffering than patients and that euthanasia is most often reported in cases with severe physical symptoms, severe loss, and limited life expectancy.<sup>12;13</sup> Our findings suggest that the attending physician when understanding the patient's suffering does not fully explore the patient's perspectives on the constituent elements of unbearable suffering. We do know from earlier research that the attending physician often has difficulty coming to understand the patient's unbearable suffering<sup>11;12;14</sup> and choosing between his/her own perspective and that of the patient.<sup>4</sup> We assume that improving the attending physician's knowledge of the constituent elements of unbearable suffering would influence his/her assessment and would improve the transparency of decision-making regarding a request for EAS.

According to the Dutch Royal Medical Association guideline, it is the independent consultant's task to map and report suffering from both the patient's perspective and the attending physician's perspective.<sup>27;28</sup> However, our study shows that the independent doctor's reporting was least similar to the patient's perspective on unbearable suffering. This was most apparent regarding the elements of the socio- environmental and existential themes; the element 'life is over' was hardly mentioned. It is unknown whether this is due to a lack of systematic exploration of unbearable suffering, differences in views regarding the permissibility of euthanasia<sup>17</sup>, or their role in the decision-making. It raises the question whether there is a relation between the under-reporting and assessment problems related to unbearable suffering as reported by the RRCs.<sup>18</sup>

Our study suggests that the relative might understand the patient's unbearable

suffering very well, and that her/his knowledge about the socio-environmental elements might exceed the understanding of the attending physician and the independent doctor. This might be related with a strong physical need to find alignment in order to feel comfortable with their deceased loved ones decision. The findings of this study corroborate those of studies that conclude that close relatives and family caregivers play an important role in the practical and emotional aspects of patient care, that patients talk about their wishes concerning the end of life and the possible euthanasia request with a close relative first<sup>21,29</sup>, and that they are fully engaged in the end-of-life decision-making.<sup>29,30</sup> Our findings evoke the questions whether and how the relatives' knowledge of the patient's unbearable suffering contributes to better understanding the patient's perception of unbearable suffering for both attending physicians and independent doctors.

Our earlier study shows that patients believe that elements of the medical and socio-environmental themes may cause suffering, but do so especially when they are accompanied by psycho-emotional and existential problems until the suffering becomes unbearable.<sup>20</sup> Our current research shows that attending physicians and independent doctors might better understand the constituent elements of unbearable suffering if they systematically explored these four themes.

One limitation of our study is that the patient, his/her closest relative, and the attending physician were interviewed at different times. Patients were interviewed shortly after they explicitly requested EAS. Relatives and attending physicians were interviewed on the same day, approximately 4 weeks after the death of the patient. This retrospective design could affect the reliability of these data. As a result of the recruitment method, we might have selected attending physicians with an affinity for the study subject, resulting in a better understanding of unbearable suffering than their colleagues have. Another limitation is that most eligible patients were first approached by their attending physicians, which might have resulted in an over-representation of unproblematic cases. The independent doctors' perspectives on the constituent elements were extracted from their reports to the RRCs, which is also a limitation. Furthermore, the differences in stimuli introduced by the in-depth interview design might have influenced the phrasing of the elements so that agreement could have been underestimated.

The strengths of our study include the multi-perspective method and the representativeness of the 20 cases, which varied in diagnoses, demographics, and geographic backgrounds. Another strength is the timing of the interviews with patients shortly before euthanasia, in the same conditions as the independent consultation. Given this study's representativeness and the timing of the patients' interviews, and despite its limitations, it contributes significantly to understanding the perceptions of the unbearable suffering of patients, relatives, and attending physicians in cases where there is agreement about unbearable suffering. The study

also contributes to understanding which of these elements independent doctors report to the RRCs.

## Conclusions

Our study shows that, despite agreement about unbearable suffering, the attending physicians' knowledge of the patient's perception of unbearable suffering is incomplete. The differences are most apparent in the socio-environmental themes, but also appear in elements of the medical, psycho-emotional, and existential themes. Drawing on our analysis, we hypothesize that a systematic exploration of medical, psycho-emotional, socio-environmental, and existential elements of suffering may improve the knowledge of attending physicians, independent doctors, and RRC members. Making knowledge about the patient's perspective may improve the transparency of the decision-making and the assessment of the rules of due care. Our study has implications for healthcare policy-makers, the professional education of physicians, and the development and implementation of a framework fit to systematically explore the perspectives on unbearable suffering of patients who request EAS.

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Appendix 1. Code book: themes, categories, and codes of suffering named by patients explicitly requesting EAS.

Themes	Categories	Codes
Medical	Physical symptoms	General symptoms: pain, fatigue, general malaise, feeling miserable, physical deterioration, changed appearance Gastrointestinal symptoms: eating and drinking problems, anorexia, nausea, vomiting, loss of weight, defecation problems Nervous and locomotor symptoms: deterioration of locomotor function, mobility, and coordination; loss of balance; dizziness Dyspnea Incontinence
	Cognitive symptoms	Confrontations with cognitive deterioration, deterioration of ready knowledge, inability to concentrate, inability to participate in conversations, slow-wittedness, loss of memory
	Psychiatric symptoms	Loss of emotional control, loss of emotions, insomnia, de-realization, depersonalization, suicidal ideation, depression, identity crisis, fear, addiction
	Effects of medical treatment	Side effects of chemotherapy, radiotherapy, psychopharmaceuticals, and morphine. Complications of operations
	Decline	Physical, cognitive, and emotional
Psycho-emotional	Loss of self	Loss of the following: Autonomy: independence and being in control Expression of personal traits: social-mindedness, readiness to help others, being of significance, caring, pride in achievements Communication style: considerate of the views of others, open Specific personality descriptors: modest, honest, loyal, consistent, interested, rational, humorous, relativistic, optimistic, uncomplaining, not overly emotional Favorite activities: active outdoor events and “enjoying life”, e.g., going out for dinner, etc.
	Fears of future suffering	The course of the illness and dying: getting worse, uncontrollable symptoms, a horrible death Cognitive decline: deterioration, loss of control of the mind, loss of community, becoming insane with fear, being unable to recognize surroundings Consequences of palliation: side effects of treatment, including morphine Physical decline: deterioration, dullness, urinary incontinence, mechanical ventilation Physical symptoms: nausea, pain, choking, dyspnea Loss of self-determination: being totally unable to do anything, loss of control, vegetative state, being bedridden Emotional aspects: suffering, anxiety




	Dependency	Being dependent, loss of physical functions of everyday living, being bedridden
	Loss of autonomy	The way others treat you: patient role, being treated as a hothouse plant, not being seen as a human being, being pressured to make decisions Loss of self-determination: loss of direction, loss of making your own decisions, loss of independence, impaired daily functioning Desire to control death: not wanting to experience the end stage of the disease, not wanting to suffer to the end, desire to have a say about your own dying, wanting your preferred way of dying, wanting to die with dignity, wanting no prolonged dying, desire to die at home, wishing to have some influence on the memories left behind
	Being worn out	Not being able to stand it anymore, demoralization, being so tired, exhausted by the treatments, tired of fighting the illness
Socio-environmental	Loss of social significance	Feeling insignificant for society or loved ones. Loss of social, occupational or family roles, or status
	Communicative problems	Inability to participate in conversation, inability to communicate
	Discontent about residential circumstances and quality of care	Residential: being unable to go home, nursing home as a prospect, unsuitable living conditions Quality of care: poor quality of professional care, disappointment in informal care
	Being a burden	Being a psychological or physical burden to the next of kin and the formal and informal caregivers
	Loneliness	Loss of loved ones, withdrawal, isolation, being left alone
	Biographical aspects	Family history, occupational history, autobiography, social background, bad marriage, sexual abuse, family trauma (e.g., war)
Existential	Loss of important and pleasurable activities	Being unable to participate
	Hopelessness	Absence of any hope of improvement, absence of or degrading future prospects, nature and progress of the disease, unsuccessful suicide attempts
	Pointlessness	Loss of joie de vivre, loss of purpose in life, loss of the will to live
	Life is over	Being tired of life or weary of living, a feeling of nothing to live for

Appendix 2. Characteristics of patients whose request for EAS was granted.

Patient number	Gender	Age (years)	Diagnosis	Residence
1	Female	53	Lung cancer	Hospice
2	Male	43	Liver cancer	Hospice
3	Male	88	Colon cancer	Hospice
4	Male	54	Gastric cancer	Home
5	Female	71	Gallbladder cancer	Home
6	Female	49	Breast cancer	Home
7	Female	70	Parkinson's disease	Home
8	Female	65	Breast cancer	Home
9	Male	62	Kidney cancer	Home
10	Male	83	Lung cancer	Home
11	Female	80	Pain syndrome	Nursing home
12	Male	75	MND	Home
13	Female	77	Pain syndrome	Home
14	Male	77	Bladder cancer	Home
15	Female	65	Pain syndrome	Hospice
16	Male	61	Alzheimer's disease	Home
17	Male	65	MND	Home
18	Female	76	MND	Hospice
19	Female	57	Sigmoid cancer	Home
20	Female	55	Nasopharyngeal cancer	Home

EAS = Euthanasia or physician-assisted suicide; MND = motor neuron disease

Level of education	Occupation	Marital status	Number of children	Religion
Intermediate	Administrator	Married	2	-
High	Teacher	Single	0	Humanism
Intermediate	Director	Widower	2	-
High	Manager	Married	2	-
Basic	Housewife	Widow	3	-
High	Manager	Married	2	-
High	Teacher	Married	2	Humanist
Intermediate	Home care	Divorced	2	There is more
High	Manager	Married	0	Secular
High	Businessman	Married	4	-
Basic	Housewife	Married	4	-
Basic	Manager	Married	5	-
High	Psychotherapist	Widow	3	Humanist
Intermediate	Salesman	Married	2	-
Low	Housewife	Widowed	2	-
High	Director	Married	2	-
Intermediate	Real estate agent	Married	3	Catholic
Intermediate	Housewife	Widowed	2	Protestant
High	Lawyer	Divorced	2	-
Intermediate	Accountant	Married	3	Protestant



‘Iedere taal is schoon voor wie luisteren kan.  
Want in elke taal zingt de gedachte  
van een volk  
en de ziel van een mens,  
en die muziek is universeel’

Johan Daisne



# *Chapter 6*

Linguistic analysis of face-to-face interviews with patients  
with an explicit request for euthanasia,  
their closest relatives, and their attending physicians:

The use of modal verbs in Dutch

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## Abstract

**Background** The literature, field research, and daily practice stress the need for adequate communication in palliative care. Although language is of the utmost importance in communication, linguistic analysis of end-of-life discussions is scarce.

**Aims** Our aim is twofold: we want to determine what the use of four significant Dutch modal verbs expressing volition, obligation, possibility, and permission reveals about the concept of unbearable suffering and about physicians' communicative style.

**Methods** We quantitatively (TextStat) and qualitatively (bottom-up approach) analysed the use of the modal verbs in 15 interviews with patients requesting euthanasia or physician-assisted suicide, their physicians, and their closest relatives.

**Results** An essential element of unbearable suffering is the patient's incapacity to perform certain tasks. Further, the physician's preference for particular modal verbs reveals whether his attitude towards patients is more or less patronising and more or less appreciative.

**Conclusions** Linguistic analysis can help medical professionals to better understand their communicative skills, styles, and approach to patients in end-of-life situations. We have shown how linguistic analysis can contribute to a better understanding of physician–patient interaction. Moreover, we have illustrated the usefulness of interdisciplinary research in the medical domain.

## Background

The Belgian Health Care Knowledge Centre,<sup>1</sup> recommends that the basic training of medical care professionals include common subjects across all curricula, e.g. control of symptoms, communication skills, social problems, and spiritual needs. In his inaugural lecture, Vissers<sup>2</sup>, the first Dutch lecturer in palliative care, makes a plea for better communication training for end-of-life settings: healthcare professionals need to communicate openly and honestly with one another and with patients and their family members. Menten and van Orshoven stress the need for palliative teams to know how communication works and what influences it.<sup>3</sup> O'Connor et al. plead for a common language in palliative care 'that promotes universal understanding of the normalcy of death and the principles of palliative



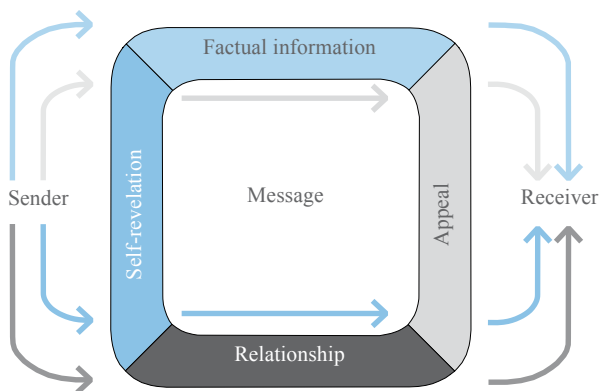
care practice<sup>7, 4</sup>

The literature (e.g. Fine et al.<sup>5</sup>), field research, and daily practice stress the importance of adequate communication in palliative care. A lack of communication between patients and family members about the imminent death can even accelerate the end of life.<sup>6</sup> Fifty percent of the family members of people who died in hospital considered communication a problem.<sup>7</sup> Patients do feel less frightened and less confused when information is provided more than once and through different communication channels.<sup>8</sup> Report 115C of the Belgian Health Care Knowledge<sup>1</sup> makes a similar statement:

Communication with patients and families at the end-of-life is very important. The literature about needs concluded to the need for stepwise delivered information and for sensitive communication with patients and their informal carers. Clear communication with the patient is not only beneficial for the palliative patient and his family but as well for the well-being of the caregiver.

During the anamnesis or the catamnesis, the physician asks specific questions to gain medically relevant information from the patient. The physician in return provides the patient with information about his illness and its treatment. From a linguistic point of view, such communication processes entail more than a technical, factual exchange of information. Schulz von Thun's Four Sides Model<sup>9</sup> (Figure 1), which was developed for communication in general, but also applies to medical communication, shows that there is more at stake than a simple transfer of messages. The relationship between the communicative participants is complex as it changes continuously and includes the social and psychological dimensions of self-revelation, appeal, and rapport between the participants.

Figure 1. Schulz von Thun's Four Sides Model



Schulz von Thun<sup>9</sup> describes not only the content of a message, but also its relational aspects. The relational aspects are situated along two major axes: patronising ⇔

giving autonomy and contempt ⇔ appreciation. Those features enable us to define the attitude that a person displays when engaged in communication as being more or less patronising, more or less appreciative, etc.

As an essential and evident communication tool, language is the preferred study object of applied linguistics. There is, however, little linguistic research about end-of-life communication. Our multidisciplinary research project, a cooperation between the Subfaculty of Languages and Communication, KU Leuven, and the Radboud University Nijmegen Medical Centre aims at filling that gap. Rimal and Lapinsky recommend such a multidisciplinary approach to health communication.<sup>10</sup> Discursive approaches in palliative care research offer new ways of seeing palliative care: they provide ‘a lens through which to examine the development of community values and attitudes to issues of death, and end of life care’.<sup>11</sup> In this paper, we report on our analysis of one particular aspect: the use of four Dutch modal verbs in communication in end-of-life settings. How do the different communicative participants use the verbs that express volition, obligation, possibility, and permission? What do they reveal about the interpretation of the concept of unbearable suffering? What does the use of these verbs reveal about the individual physician’s behaviour?

## Methods

### Research data

The research material consists of 15 interviews with five patients, the closest relative of each, and the general practitioner of each. The interview data were previously used for a qualitative study aimed at understanding the constituent elements of suffering of patients who explicitly requested euthanasia or physician-assisted suicide (EAS) and at better understanding unbearable suffering from the patient’s perspective. The original study, carried out in the Netherlands between April 2008 and July 2009, included 31 patients, 31 family caregivers, and 28 physicians. The Medical Ethics Committee at the Radboud University Nijmegen Medical Centre approved this study. The patients were recruited with the assistance of the Support and Consultation on Euthanasia in the Netherlands (SCEN) network. All participants signed an informed consent form. The patients were interviewed a short time before the EAS took place. The family caregiver and the physician were interviewed approximately 4 weeks after the death of the patient. All the in-depth interviews took place on location and lasted 30 to 120 minutes. All patients were interviewed alone to ensure that the caregiver’s presence did not influence the information they gave. The interview guide was based on the original research question and a literature review.<sup>12</sup> The purpose of the guide was to help explore the development of the request, the constituent elements of suffering, and the contribution of these elements to the development of unbearable suffering. The interviewer (MD), an experienced general practitioner and SCEN specialist,

closely followed the interview line that the patient brought forward. The interviews were audio-taped and transcribed verbatim. Demographics were collected before the interviews. For the linguistic analysis, five cases were randomly selected in order of the date of the interview, alternating between male and female patients.

### **Data analysis**

We started the analysis with a small-scale literature review for which we searched the online databases EBSCO, Science Direct, and Web of Knowledge to find comparable studies.

We used TextStat 2, a word frequency and collocation programme, for the quantitative part of the data analysis.<sup>13</sup> We counted and listed all the variants of the modal verbs. We determined the immediate context in order to identify the communicative participants linked to the verbs.

We used a bottom-up approach for the qualitative analysis. This kind of approach is data driven, and it uses the corpus material rather than the literature as the main source of information. Moreover, the linguists in the research team were not aware of the interviewees' profiles during their linguistic research. The approach we used for the qualitative part of our research is the discourse analysis, a research method that examines larger chunks of language rather than single sentences. This approach enables us to determine the relationship between communicative participants, as Crystal's<sup>14</sup> definition of discourse analysis clarifies:

The study of how sentences in spoken and written language form larger meaningful units such as paragraphs, conversations, interviews, etc.

- a. How the choice of articles, pronouns, and tenses affects the structures of the discourse
- b. The relationship between utterances in a discourse
- c. The moves made by speakers to introduce a new topic, change the topic, or insert a higher role relationship to the other participants.

### **Definitions**

In line with Dutch law, we have defined euthanasia<sup>15</sup> as the termination of life at the explicit request of the patient by a physician with the intention of ending hopeless and unbearable suffering. We define physician-assisted suicide as the act of ending one's own life with the aid of a physician who helps bring about death for compassionate reasons. A request for EAS was said to be 'explicit' when the patient had specifically asked a physician to help end the patient's life. Dees et al.'s literature review<sup>12</sup> states that there is no generally accepted definition of unbearable suffering. On the basis of interviews with patients who requested EAS, Dees<sup>16</sup> describes the concept as follows:

...while suffering is rooted in the symptoms of illness and aging, the existential

and psycho-emotional themes determine how much hope there is and whether the patient is able to bear the suffering. Unbearable suffering can only be understood in the continuum of the patient's perspectives on the past, the present and expectations of the future. Without hopelessness, there is no perception of unbearable suffering.

Dees' description explicitly refers to modal aspects by using the verb phrase *is able to*. Modality has a different meaning in linguistics than in medicine. Haeseryn et al.<sup>17</sup> define modality as:

De in een zin uitgedrukte visie van de spreker of schrijver op de verhouding tussen de in die zin weergegeven situatie en de werkelijkheid en/of zijn attitude met betrekking tot die situatie. [The opinion that the speaker or writer expresses in a sentence about the relation between the situation described in the sentence and reality; or his attitude toward the situation.]

Modality is a linguistic device that we use to express a perspective on reality: it shows how someone feels about the content of a message (e.g. *Luckily* he succeeded) or how a message is related to reality (e.g. *Perhaps* he will succeed). In Dutch, modality can be expressed in different ways, one of the most frequent being the use of modal verbs. For our analysis, we selected the modal verbs expressing obligation 'moeten' (*to have to*), volition 'willen' (*to want*), possibility 'kunnen' (*to be able to*), and permission 'mogen' (*to be allowed to*). On the basis of the topics addressed in the interviews and touched upon by the interviewees (e.g. what the patients can or cannot do, what their wishes are), we expected these modal verbs to be revealing in the context of a request for EAS.

## Results

### Literature search

In September 2010, we searched the online databases EBSCO, Science Direct, and Web of Knowledge for relevant articles, using the combined search terms end-of-life, palliative, communication, and physician-patient. We limited our search to the last two decades (1990–2010). None of the 72 articles we collected has clear indications in either the abstract or the discussion and conclusion section of the use of linguistic parameters in analysing the material. Some articles do claim that they use a discourse analytical method<sup>18</sup> or a qualitative content analysis.<sup>19,20</sup>

Nineteen of the 72 articles are based on doctor–patient communication. Four of them have a research design similar to our own, as their data consist of or include interviews with patients, their physicians, and their relatives or caregivers. Yedidia<sup>21</sup> challenges the use of protocols to deal with difficult communication situations. Back et al.<sup>22</sup> refer to the need for better communication skills. Quill<sup>23</sup>

makes a plea for initiating end-of-life discussions earlier and more systematically because, for example, this could enable patients to make better informed choices. Clayton et al.<sup>24</sup> developed a question prompt list that facilitates the communication between patients and physicians.

### Analysis of the modal verbs

The corpus consists of 72,874 words in total, grouped as Table 1 shows. Table 2 shows the frequency of the modal verbs per 1000 as they occur in the complete corpus and in the subcorpora of the patient, physician, and relative (Table 1). The verb ‘kunnen’ expressing possibility is the most frequently used modal verb. Except for ‘willen’, the modal verbs are used more frequently in the patients’ discourse than in the physicians’ or the relatives’. For each modal verb we discuss some striking findings in more detail.

### ‘Kunnen’

The modal verb ‘kunnen’ (can) occurs 669 times (9.22 per 1000 words) in the complete corpus. We analysed the data to see who the verb ‘kunnen’ is associated with by determining the subject of the verb. In example 1, the subject of *can<sub>1</sub>* is the patient and the subject of *can<sub>2</sub>* is the physician. We have translated the examples literally to reflect the use of the Dutch modal verbs accurately. Appendix 1 provides the original Dutch extracts.

*1. ‘Then I immediately said, yes, if you are unconscious or you can<sub>1</sub> no longer make it clear to me that you want euthanasia at that moment, yes, then I can’t do it.’ (physician - case 1)*

The patients associate the verb ‘kunnen’ more often with themselves than the physicians and the relatives do (patients: 42%, physicians: 21%, relatives: 17%). In other words, the patients express what they themselves are able to do. The complete corpus confirms this tendency of ‘kunnen’ to be associated with the patients. In 38.12% of all occurrences (255 of 669), the verb is linked to the patient (patient discourse: 41.96%, physician discourse: 39.3%, and relative discourse: 35.3%). This aspect becomes even more relevant to the definition of the concept of unbearable suffering if we take into consideration the use of ‘kunnen’ in combination with a negation (*not* be able to). In 38.57% of the occurrences (258 of 669) ‘kunnen’ is used negatively, referring to the fact that one is not able to do something. When the patient is the subject of the verb, the incidence rises to 51.16% (132 of 255). In other words, in more than half of the cases, it described what the patient is not able to do.

*2. ‘The fact that I am sitting here dozing and again I can’t join in.’ (patient - case 11)*

If we more closely study the sentences with ‘kunnen’ in combination with a negation, we notice that in almost half the cases (123 of 258 or 47.67%), the negation is ‘niet meer’ (*no longer* or *not anymore*). This type of construction implies a comparison between the past (able to do something) and the present (not able to do something). Example (3) contains three instances of that construction.

3. *‘Let’s say, if I can no longer see, can no longer communicate, yes then it is completely, and can no longer talk, yes then of course it no longer makes any sense at all.’* (patient – case 1)

In 89 of the 123 sentences with *can no longer* (72.36%), the subject of the verb is the patient [other sentences: an impersonal subject (15 times), a general reference to ‘everyone’ (8 times), physician (6 times), relative (5 times)].

### ‘Moeten’

The modal verb ‘moeten’ (must) expressing obligation occurs 308 times in the research material (4.24 per 1000 words) and has the highest incidence in the patients’ discourse. Similarly to the verb ‘kunnen’, the patients associate the verb with themselves more frequently than the physicians and the relatives do. They express in that way that they themselves are obliged, or feel obliged, to do something (patients: 40.97%, physicians: 26.26%, relatives: 30.16%). In the complete corpus, the tendency to link the verb ‘moeten’ with the patient (79 of 308 occurrences or 25.65%) is less prominent than that of the verb ‘kunnen’.

4. *‘Yes, then I myself have to make the decision to die.’* (patient – case 29)

In Dutch, ‘moeten’ + negation is replaced with the verb ‘hoeven’ + negation, which has a frequency of 0,53 per 1000 in the data. In 16 of the 39 sentences with ‘hoeven’ (have to) (41.03%), the negated obligation is linked to the patient, as it is in example 5.

5. *‘I am glad that she didn’t have to go through this’* (relative – case 11)

### ‘Mogen’

The modal verb ‘mogen’ (may) that expresses permission, has a rather low frequency (0.49 per 1000 words) compared to the other modal verbs in this paper, but it is relevant because patients with an explicit euthanasia request need official permission from a SCEN specialist to have EAS granted. It has to be said, however, that no instance of the verb ‘mogen’ in our data is related to that aspect.

Again we checked with whom the verb is associated by analysing its subject. Remarkably, but not surprisingly, the physicians never link the verb to themselves, while the patients (35.71%) and the relatives (38.46%) do. In almost one-third of its occurrences, ‘mogen’ (30.66%) is associated with the patient.

6. *'You may cry because I can take the tears.'* (physician – case 23)

In 30.56% of its occurrences, the verb 'mogen' is combined with a negation, expressing an absence of permission, sometimes in a general context (example 7).

7. *'That we think that you may not intervene here, but yes, why do we do it with our pets and not with people?'* (patient – case 11)

### **'Willen'**

The frequency of 'willen' (want) in the subcorpora differs from frequencies of the other modal verbs. 'Willen', expressing volition, occurs most frequent if the physicians' discourse (physician: 5.06 per 1000 words; patient: 4.87 per 1000 words; relative: 3.94 per 1000 words). In 64.2% of all occurrences, it is the patient to whom the verb is linked; in other words, the patient is the person who wants something (the volitional agent, in semantic terms). In the parts of the discourse that are reported speech, the proportion rises to 68.5%.

8. *'Because she didn't want to become dependent on other people, that was the main thing.'* (physician – case 1)

In 29.18% of the occurrences (96 of 329), the verb 'willen' is used in combination with a negation. Of the negations, 19.8% (19 of 96) consist of 'niet meer' (*no longer or not anymore*). For the definition of the concept of unbearable suffering it is revealing that 81.28% of the negative sentences (78 of 96) is linked to the patient (other sentences: relative 15x, physician 9x, impersonal construction 3x, general reference 2x). The interviews deal with what the patient does not want or no longer wants. Example 9 sums up some utterances from case 11.

9. *'I don't want agony.'* (patient – case 11)

*'Then I don't want to suffer to the end.'* (patient – case 11)

*'I don't want homecare 24 hours a day.'* (patient – case 11)

*'But that was not the main reason to say I don't want this any longer.'* (relative – case 11)

*'She didn't want to end up bedridden.'* (physician – case 11)

*'I don't want to be a burden to my children.'* (physician – case 11)

### *Modal verbs in the physicians' discourse*

Schulz von Thun<sup>9</sup> describes not only the content of a message (Figure 1) but also its relational aspects. The relational aspects are situated along two major axes: patronising ⇔ giving autonomy and contempt ⇔ appreciation. The attitude that a person displays while engaging in communication can be defined as being more or less patronising, more or less appreciative, etc. The modal verbs 'moeten', 'mogen' and 'willen' are relevant for the axis patronising ⇔ giving autonomy.



To determine whether the use of modal verbs is also indicative for a physician's attitude, we examined the physicians' discourses in more detail. Table 3 shows how the individual physicians use our four modal verbs discussed above. For the modal verbs 'kunnen' and 'mogen' the differences are not statistically relevant ( $p > 0.1$ ); they are for 'moeten' ( $p < 0001$ ) and 'willen' ( $p < 0.01$ ). This implies that the high and low scores for these verbs indicate the attitude of the physicians on the axes that Schulz von Thun<sup>9</sup> describes.

Table 4 shows which of the four modal verbs each physician most often uses. Physicians 1 and 11 use 'willen' more frequently, while physician 29 more frequently uses 'moeten'. There are too few occurrences of 'mogen' to draw valid conclusions. If we consider to whom the verbs 'willen' and 'moeten' are linked, we see some remarkable results. Physicians 1 and 11 link the verb 'willen' to the patient in two-thirds of its occurrences (case 1: 64.84% and case 11: 65.21%). This illustrates that they value the patient's wishes more than their own, as is illustrated in example 10:

*10 'I think it's a pity that she is taking this decision, and then I thought, well now, it's simply what she wants.'* (physician – case 11)

When physician 29 links the verb 'moeten' with a person (and not with an abstract concept such as euthanasia), the person is the patient in 79% of the occurrences. The numbers enable us to make some cautious observations about the physicians' attitudes. Physicians 1 and 11 are clearly at the autonomy end of the axis, while physician 29 can be characterised as having a more patronising attitude and communication style.

These linguistic conclusions confirm the interviewer's perceptions of the interviewees. For example, the physicians in cases 1 and 11 extensively explored the patients' motives and openly discussed feelings and opinions, aiming at a shared decision, despite physician 11's earlier conviction that he did not want to perform EAS anymore.

Table 1. Composition of the corpus material

Subcorpora	Number of words	Percentage of
Patients	17,694	24.28
Physicians	23,927	32.83
Relatives	31,253	42.89
Total corpus	72,874	100

Table 2. Frequency of the modal verbs (per 1000 words)

	Total corpus	Patients' discourse	Physicians' discourse	Relatives' discourse
'kunnen'	9.22	9.92	8.4	9.44
'moeten'	4.24	4.7	4.14	4.07
'mogen'	0.49	0.79	0.34	0.41
'willen'	4.53	4.87	5.06	3.94

Table 3. Use of the modal verbs by the different physicians (per 1000 words)

Case number	'kunnen'	'moeten'	'mogen'	'willen'
physician case 01	8.25	3.56	0.25	7.77
physician case 11	8.8	3.72	-	7.78
physician case 18	7.16	4.52	0.62	3.58
physician 1 case 23*	8.97	1.42	-	2.83
physician 2 case 23	9.98	2.81	1.12	3.93
physician case 29	8.86	6.64	-	4.03
Total	8.4	4.14	0.34	5.06

\*Two physicians were interviewed for case 23

Table 4. Use of the modal verbs by the different physicians (in percentage)

Case number	'kunnen'	'moeten'	'mogen'	'willen'	Total
physician case 01	42.5	17.5	1.25	38.75	100
physician case 11	43.33	18.33	-	38.33	100
physician case 18	42.16	18.63	3.92	22.55	100
physician 1 case 23	67.86	10.72	-	21.43	100
physician 2 case 23	53.33	16.17	6.67	23.33	100
physician case 29	45.83	33.33	-	20.83	100
Total	47.18	23.24	2.11	27.64	100

## Discussion

In this pilot study, we have analysed interviews with patients, relatives, and physicians about their opinions of unbearable suffering in the context of a request for EAS, a subject that goes beyond the conversations in everyday practice. Our research shows that the way communicative participants use modal verbs is indicative of their attitudes to end-of-life decisions and that the way physicians use these verbs is indicative of their communicative style and skills. Our analysis confirms that 'discourse analysis has benefits in revealing taken-for granted and hidden aspects of communication in palliative care'<sup>11</sup>.

In the literature review, we discussed four papers that, as this paper does, use interviews with patients, relatives, and physicians as research data. Since the four papers have no linguistic orientation, a relevant comparison with our results is not feasible.

The most frequently used modal verb in this study is ‘kunnen’, expressing ability. The modal verbs (except for ‘willen’) occur most frequently in the patients’ discourse. In the overall corpus, the modal verbs are most often linked to the patient: it is the patient who can do something, who is allowed to do something, or who wants something.

Our analysis yielded some remarkable findings with regard to the concept of unbearable suffering that are clearly in line with Dees<sup>12;16</sup> description of the concept and more in particular with her reference to the perspectives of the past, present, and future. With regard to the verb modal verb ‘kunnen’ we can conclude that an essential element of unbearable suffering and of the decision to choose EAS is the fact that a patient is no can perform certain activities. The analysis of the modal verb ‘willen’ shows that, in deciding about EAS, the volition of the patient plays an important role. However, what he does not want is more important than what he does want.

With regard to the use of modal verbs in the separate physician’s discourses, we can conclude that the differences we noticed are indicative of the physicians’ communicative style and attitude. The communicative styles and attitudes can be defined with regard to the axes patronising ⇔ giving autonomy and contempt ⇔ appreciation. Our analysis of a single linguistic feature of the discourse confirms conclusions drawn from a content analysis of the interviews. Physicians who are reported to be more cooperative and more open for discussion use the modal verbs ‘moeten’, ‘mogen’ and ‘willen’ differently. Physicians with these characteristics are at the appreciative and giving autonomy end of the axis.

## Conclusion

The results from this pilot study of a particular linguistic aspect, that is modal verbs, suggest that linguistic analysis can help medical professionals to better understand their communicative skills and styles, and their communicative approach to patients in end-of-life situations. An analysis of real-life discussions between patients and physicians about end-of-life decision-making would help us make an even stronger case for the conclusions put forward.

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## Appendix 1 Original Dutch examples

1. Toen heb ik ook meteen gezegd van ja, als jij bewusteloos bent of mij niet meer kan duidelijk maken dat je op dat moment euthanasie wil, ja dan kan ik het niet doen
2. Het feit dat ik euh hier zit te suffen en dus euh ja ook weer niet mee kan komen
3. Zeg maar eh, dan eh als ik niet meer kan zien, niet meer communicatief kan zijn, ja dan is het wel helemaal, en niet meer kan praten op zich, ja dan heeft het helemaal geen zin meer natuurlijk
4. Ja dan moet ik zelf het besluit nemen om te sterven
5. Ik ben blij dat zij dit niet heeft hoeven meemaken
6. Je mag van mij best janken want ik kan wel tegen tranen
7. Dat wij hier vinden dat je niet in mag grijpen, maar ja waarom doen we het dan bij onze huisdieren wel en bij mensen niet
8. Want ze wilde niet afhankelijk worden van mensen, dat was het belangrijkste
9. Ik wil geen lijdensweg  
 Dan wil ik niet lijden tot het eind  
 Ik wil het niet thuiszorg vierentwintig uur  
 Maar dat is niet de belangrijkste reden geweest om te zeggen ik wil dit niet meer  
 Ze wilde niet in bed komen te liggen  
 Ik wil niet tot last zijn voor mijn kinderen
10. Ik vind het jammer dat ze hiertoe besluit en toen dacht ik van, nou ja, zij wil het gewoon



Ik beloof dat ik de geneeskunst zo goed als ik kan zal uitoefenen ten dienste van mijn medemens.

Ik zal zorgen voor zieken, gezondheid bevorderen en lijden verlichten.

Ik stel het belang van de patiënt voorop en eerbiedig zijn opvattingen.

Ik zal aan de patiënt geen schade doen.

Ik luister en zal hem goed inlichten.

Ik zal geheim houden wat mij is toevertrouwd.

Ik zal de geneeskundige kennis van mijzelf en anderen bevorderen.

Ik erken de grenzen van mijn mogelijkheden.

Ik zal mij open en toetsbaar opstellen, en ik ken mijn verantwoordelijkheid voor de samenleving.

Ik zal de beschikbaarheid en toegankelijkheid van de gezondheidszorg bevorderen.

Ik maak geen misbruik van mijn medische kennis, ook niet onder druk. Ik zal zo het beroep van arts in ere houden.

Dat beloof ik.

De Nederlandse artseneed (2003)



# *Chapter 7*

## General Discussion

Marianne K. Dees

This thesis examines unbearable suffering and decision-making in connection with requests for euthanasia or physician-assisted suicide (EAS). This chapter discusses various relevant issues: the quality and limitations of the individual results of the research questions, the main findings, and the conclusions of the chapters and their relationship. Further, implications for practice, education, and future research are considered.

## Background

The idea for this thesis took shape in the years after the Dutch legalisation of EAS in 2002.<sup>1</sup> The public, professional, and ethical discussion was dominated by the theme ‘what unbearable suffering is and who decides what it is’. Consequently, this thesis explores unbearable suffering and decision-making in the context of an explicit request for EAS from three perspectives: those of the patient, the relatives, and the attending physician. In fact, the patient initiates the process by sharing his/her wish for a possible future request with relatives and the attending physician [most often the general practitioner (GP)]. This physician considers her own willingness to consider granting the request and shares her view of EAS with the patient. If the request becomes explicit and if the physician is willing to grant it, she has to consult an independent colleague. The designated independent physician, usually a Support and Consultation on Euthanasia in the Netherlands (SCEN) consultant, should give her opinion about the first four requirements of due care as stated in the Dutch Euthanasia Act of 2002 (Box 1).<sup>1</sup> By law, a Regional Review Committee (RRW) must evaluate the adherence to the requirements of due care after each individual EAS has taken place. If everything is in order, the case is not presented to the state prosecutor.

Before the legalisation of EAS in 2002, pro-and-con discussion dominated the public debate. After legalisation, the scope shifted to: ‘what unbearable suffering is’. Public opinions about unbearable suffering in the context of a request for EAS are subject to change, and the Dutch law accommodates reflection on changes in patients’, physicians’, public, professional, and ethical opinions about unbearable suffering. Thus, ‘unbearable suffering and EAS’ in the context of dementia, psychiatric illnesses, and being tired of living are included in this discussion.

Nowadays in the Netherlands, EAS is no longer seen as an isolated subject brought forward by individual patients but as a possible end-of-life preference that should be discussed in the context of palliative care and end-of-life decision-making.<sup>2-5</sup> The focus of the research questions in this thesis is on unbearable suffering. Patients’, relatives’ and GPs’ perceptions of unbearable suffering were explored; the decision-making process was brought to light, and the constituent elements of cases where there was agreement about unbearability were compared.

## Box 1 Criteria for euthanasia or physician-assisted suicide

Euthanasia or physician-assisted suicide legally requires that the six criteria for due care of Article 293, paragraph 2, of the Dutch Penal Code<sup>1</sup> are met.

The treating physician must:

- a. Be convinced that the patient's request is voluntary and well-considered
- b. Be convinced that the patient's suffering is unbearable and hopeless
- c. Inform the patient about his/her situation and prospects
- d. Be convinced, as the patient must also be, that there is no other reasonable solution for his/her situation
- e. Consult at least one other independent doctor, who must see the patient and give his/her written opinion about whether the first four criteria have been satisfied
- f. Use all due care in terminating the life or assisting in the suicide

## Study design

### Qualitative methods in end-of-life research

This thesis demonstrates how to use qualitative methods to better understand an ill-defined concept and provide additional information about the more than complex process of end-of-life decisions.<sup>6</sup> Although different qualitative techniques were used in the integrative review<sup>7</sup> and the analyses of the transcripts of 90 in-depth face-to-face interviews with patients, their closest relative, and their attending physician, there was enough information to answer the various research questions. The time and effort put into the recruitment strategy facilitated purposive sampling and assured us of a proper sample size to cover the range of aspects of unbearable suffering and decision-making. The assistance from the SCEN network, a local hospice, and the notice and call for patients in the journal *Right to die NL* proved to be effective in recruiting patients who explicitly requested EAS. Most of the attending physicians were willing to ask their terminally ill patients to participate in our research. Researchers and practitioners have long been concerned about burdening vulnerable patients in the last phase of their lives with research. Only in the last decade has such research become acceptable.<sup>8,9</sup> Our study shows that it is possible to carry out in-depth interviews about sensitive end-of-life issues among clusters of patients, their relatives, and their attending physicians in end-of-life situations. Patients were quite willing to participate in this research project and said that they found meaning in knowing that others would benefit from their experiences. Their individual caregivers reported that there are benefits from the opportunity for the family to talk about their deceased loved ones, their unbearable suffering, the decision-making, the EAS itself, and the period after it has taken place.<sup>10</sup> Attending physicians appreciated the opportunity to share and reflect in this project about their patients. Our findings are comparable to those of a recent systematic literature review<sup>7</sup> that shows that the ethical concerns regarding patient participation in research into end-of-life care are often unjustified. In our study, the interviews with patients, their close relatives, and their attending physicians, along with the reports of the independent consultants, provided a wealth of information.

This collective information led to an in-depth understanding of unbearable suffering and the process of decision-making accompanying a request for EAS.

### **Strengths and limitations**

The prominent strengths of our study are: (1) it took place in an environment where euthanasia is generally accepted and legally regulated; (2) we gained in-depth information from patients with an explicit request, their attending physicians, and their close relatives; and (3) we acquired all the consultation reports of the independent doctors. These strengths distinguish our study from earlier studies<sup>7</sup> of unbearable suffering that came from countries where EAS is illegal and actual requests were absent. Another strength is our network strategy, which not only provided enough participants, but also enabled purposive theoretical sampling.

A limitation is that the specific analyses were done after all the patient interviews had taken place. We were therefore unable to apply any knowledge from already completed interviews to upcoming interviews. The rapid inclusion of the participants and their limited life expectancy forced us to prioritise the actual interviewing above analysis. Especially the results from the decision-making analyses pointed to aspects that could have been further explored if we had known about them earlier. For example, we would have known about the desirability of interviewing the independent consultant about his/her opinion of unbearable suffering. We would also have observed that a participant check among close relatives and attending physicians might have added to the quality of the interpretation. A second interviewer would have facilitated earlier analysis of the interviews and a lower risk of interview bias. Another limitation is that we did not evaluate nonparticipants.

## **Main findings and discussion about unbearable suffering**

### **The patient's perspective**

On the basis of the results of the integrative review, we drafted a definition: 'Unbearable suffering in the context of a request for EAS is a profoundly personal experience of an actual or perceived impending threat to the integrity or life of the person, which has a significant duration and a central place in the person's mind'.<sup>7</sup> Our qualitative, in-depth, interview study elucidated the fact that, from a patient's perspective, unbearable suffering is the outcome of an intensive process that originates in the symptoms of illness and/or aging. Hopelessness is an essential element of unbearable suffering. Medical and social elements may cause suffering, but especially when psycho-emotional and existential problems accompany it, suffering can become unbearable. Personality characteristics and biographical aspects greatly influence the burden of suffering. 'Unbearable suffering can only be understood in the continuum of the patients' perspectives of the past, the present, and expectations of the future'.<sup>11</sup>



From a patient's perspective, unbearable suffering does not suddenly appear on the spur of the moment of the actual request. It is more than the sum of constituent elements of suffering and is dominated by existential (spiritual) and psycho-emotional elements reaching beyond the medical domain. Unbearable suffering evolves during the individual patient's life narrative in the context of personality characteristics. It crystalizes further during the course of the illness and the palliative phase when the patient has no perspective for improvement (hopelessness) and realises a permanent loss of quality of life. We conclude that a patient has a multidimensional perspective of unbearable suffering in the context of a request for EAS. The legal aspect of 'unbearable suffering' seems to have little influence on the patients' phrasing of their request.

### **The close relative's perspective**

The integrative review has already pointed out the importance of dependency, the emotional impact of loss of dignity and personal integrity, tiredness, and the fears of the circumstances of the unavoidable death rather than pain<sup>12-20</sup> in the close relatives' perspectives of patient suffering. Our qualitative interview study shows that relatives reflected the views of the patients very well in all the themes, and strikingly so in the existential theme. Patients and their relatives share a holistic view of unbearable suffering. Their perspective is not restricted to the moment of the explicit request, but to the progress of suffering caused by an intractable illness or aging.

### **The physician's perspective**

Our qualitative study underlines the fact that attending physicians, at the time patients requested EAS, realised that their patients suffered from both physical and emotional distress and that most of the common concerns of these patients were not about physical problems.<sup>13; 21-31</sup> Our study points out the reasonable similarity of thought of patients and attending physicians about the constituent elements of unbearable suffering with regard to the medical, psycho-emotional, and emotional themes, but a lack of similarity about elements within the socio-environmental theme.<sup>32</sup> These conclusions suggest that attending physicians have a less holistic perspective of unbearable suffering in the context of a request for EAS than do patients, and the physicians tend to isolate unbearable suffering from suffering in palliative care.

These findings should be placed in the context where unbearable suffering is among the criteria of lawful EAS in the Netherlands. This legal aspect seems to affect the attending physicians' idea of unbearable suffering. They appear to have a less holistic, more momentary perception of unbearable suffering that is more predetermined by the context of needing to adhere to the rules of due care.<sup>33 34</sup> They present 'unbearable suffering' as a sum of constituent elements that they need to assess in order to comply with the second criterion for lawful EAS (Box 1).

### **The perspective of the independent consultant**

Our qualitative study shows that the independent consultants (all but one were SCEN consultants) do describe elements of suffering and give their opinion about unbearability in their report for the RRCs. They give a snapshot description, and their perspective is less multidimensional than that of the patients. Their legal role seems to affect their concept of unbearable suffering. In only one case the two consulted SCEN specialists were explicit that they described unbearable suffering from the patient's perspective. In this specific case, the patient and the GP assessed the suffering as unbearable, while both SCEN consultants concluded that the suffering was not unbearable. (Despite their negative advice the euthanasia was granted and RRC assessed that the rules of due care were fulfilled.) We conclude that it would add to the transparency if SCEN consultants were explicit in which perspectives they describe in their report.

### **Suffering in palliative care and end-of-life care**

Patients' suffering is an integrated, multidimensional experience related to physical symptoms that is affected by psychological distress, existential concerns, and social-relational worries.<sup>35</sup> Palliative care aims to improve 'the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.<sup>36</sup> Patients who say their suffering is unbearable and request EAS are convinced that there are no other treatment options to improve their quality of life or to relieve their suffering (Box1). Patients' unbearable suffering in the context of an EAS request seems to be on a continuum of both decreasing quality of life and increasing suffering. Their requests result from their personal opinions of what a good life and a good death are. They see EAS as a way to end unbearable suffering and to facilitate a 'good death'. In Western countries, most patients want to die at home.<sup>37 38</sup> The role of GPs is crucial both in providing palliative home care and in granting requests for EAS in the Netherlands. In 2010, GPs carried out 90% of the reported EASs.<sup>39</sup>

As a consequence, the GP has a complex and challenging task in this continuum of the suffering of the patient and his/her family. Why is this task so complex? Firstly, GPs do not systematically investigate patients' (and relatives') perspectives of suffering, quality of life, and relief from suffering during the course of the illness.<sup>40</sup> Secondly, there is no guideline to assist the physician in assessing when a patient's suffering has become 'unbearable'. The only direction comes from the annual reports of the RRCs, which state that the unbearability must be palpable ('invoelbaar'), which makes it dependent on the empathy of the physician. This may lead to a situation in which the physician does not get the feeling of the unbearability that the terminally ill patient does suffer.<sup>41</sup> Thirdly, a GP who

concludes that the patient is in a state of unbearable suffering while all other criteria of due care are fulfilled may feel pressured to grant the request for EAS. Fourthly, the physician may be convinced of the unbearability, but fear the assessment of the RRC.

This GP task requires competences to gain an understanding of the patient's and relatives' perspectives of unbearable suffering and to use this knowledge to prevent suffering in palliative care as well as to assess the unbearability of the suffering in a request for EAS.

## **Understanding unbearable suffering**

We hypothesised that unbearable suffering is the outcome of an intensive process that originates in the symptoms of illness and/or aging. The hopelessness of the patient is an essential element of unbearable suffering. Medical and social elements may cause suffering, but especially when the illness or the aging of the patient is accompanied by psycho-emotional and existential problems, suffering easily becomes unbearable. We have also discovered that personality characteristics and biographical aspects greatly influence the burden of suffering. Their wish to have a say about their own death is often a continuation of patients' need for an autonomous lifestyle. To understand and appreciate the patient's unbearable suffering requires a full understanding of the narrative of the individual.<sup>42</sup> Unbearable suffering in the context of a request for EAS is loss of quality of life and a lack of motivation to go on living. Our findings fit very well with Maslow's humanistic psychology.<sup>43</sup> Possibly Maslow's modified hierarchy of needs (Figure 1)<sup>44</sup> can be used to provide a comprehensive approach in the conversation with patients and caregivers to explore the patients' needs. It might help us understand their suffering. The five levels of the hierarchy are:

1. The basic need of physical and psychological comfort: i.e. no suffering from pain, nausea, or dyspnoea
2. A more complex need for safety and information: i.e. no fears of dying or abandonment
3. A need for love, good relationships, and a sense of belonging: i.e. affection and acceptance in the face of devastating illness
4. A need of self-esteem: i.e. not being a burden and retention of dignity
5. Self-actualisation and motivation: i.e. things that give meaning and value to the individual's life.



Figure 1. Modified figure from Maslow 1987<sup>43</sup> and Zalenski 2006<sup>44</sup>

Our study makes it clear that suffering and unbearable suffering are strongly related to needs and quality of life. In daily practice, a ‘Problem and Needs in Palliative Care Questionnaire’ might help us proactively explore suffering from the patient’s perspective.<sup>40</sup> Given the subjectivity of this concept, physicians who want come to an understanding of their patient’s unbearable suffering should be aware of the influence that their private norms, values, and emotions have on their understanding.<sup>45</sup> Because of its complexity, understanding suffering requires a physician who is prepared to invest time and effort in a good patient–physician relationship and communication with both patient and relatives. Therefore, for best practice in end-of-life care, we can conclude that it is important to identify the patient’s and his/her relatives’ end-of life preferences in due time to facilitate the advance care planning.<sup>46, 47</sup>

## Shared decision-making and a request for EAS

Advance care planning makes it possible to systematically identify the patient’s own end-of-life preferences and take them into account in the medical decision-making. Professionals are expected to initiate end-of-life conversations<sup>48</sup> in a patient-centred way. However, there are many communicative and personal barriers to this approach, and these conversations are not yet widely accepted.<sup>49 50</sup> In the Netherlands, euthanasia and physician-assisted suicide are regarded as end-of-life issues. GPs do play a central role both in providing home-based palliative care and in granting requests for EAS. Given their role in the continuity of care, they are the most obvious candidates to guide patients and their families in end-of-life conversations. It is in line with the current Dutch public and professional opinions<sup>5</sup> to talk with patients about their end-of-life views, expectations, and limitations in good time. Our study shows that GPs rarely initiate conversations about EAS

in the context of patient's end-of life preferences. Early sharing of views is of utmost importance because the act itself is beyond normal medical practice. These conversations are necessary to provide personalised end-of-life decision-making that takes the patient's preferences into account and facilitates furnishing good end-of-life practice.

In line with earlier research that propagated shared decision-making as the gold standard in palliative care<sup>51</sup> and end-of-life communication,<sup>52</sup> our study emphasises the importance of shared decision-making as the preferred model in a request for EAS in daily practice.<sup>53</sup> Shared decision-making really puts the patient at the centre of health care<sup>54</sup> and fits very well with the complex, emotional, and often burdensome process leading to having a request for EAS granted. Shared decision-making provides strategies for discussing unrealistic expectations and how to share views, opinions, and feelings about unbearable suffering. This is especially true and important because a possible future request for EAS might cause the physicians stress and uncertainty and strain the patient–physician relationship: it is not a matter of course that the physician will grant a request. Early sharing of views is so important because the performance of euthanasia at home is beyond normal medical practice. A timely sharing of views also makes it possible to discuss what to do when the physician is not prepared to grant a possible future request and to refer the patient to another physician.

## Recommendations

This thesis shows that GPs should initiate discussions about EAS as an end-of-life issue in the palliative care trajectory. Medical education, for both undergraduates and graduates, should address end-of-life communication and end-of-life decision-making. Professionals need specific training for skills that are sensitive to avoidant and blocking behaviour (such as difficult existential communication at the end of life). In doctor–patient communication, special attention should be paid to the interaction of both the doctor and patient in their roles in shared decision-making.

Another facet that this thesis highlights is the need for aftercare for close relatives and attending physicians. A guideline for decision-making in EAS could provide a framework to improve medical practice in this area. The SCEN network seems the most obvious organisation to provide systematic support and aftercare for attending physicians. The aftercare for relatives can systematically be started by one of the professionals involved in homecare and is not necessarily restricted to the attending physician.

On the basis of the outcomes of this thesis, future research should address the development, validation, and implementation of a guideline within the context of good palliative care that provides a framework for proactive end-of-life

conversations, does justice to patients' preferences, and facilitates personalised end-of-life practice.

## Conclusions

The findings of this thesis have important implications for daily practice. Death and dying have a place in the continuity of care. Good palliative care and end-of-life care should be incorporated into regular medical practice and start before patients' and relatives' hope of a cure has disappeared. Early knowledge of the patient's end-of-life preferences is part of good end-of-life care. In countries where EAS is legalised, attending physicians should be able to talk about death and dying, independently of their own considerations and principles, with patients and relatives when the subject is relevant. This should be true even when the conversation includes a possible future request for EAS. They should give support, and if necessary, refer the patient to a colleague. The physician who is responsible for continuity of care is the most obvious choice and is the professional to initiate this conversation. This task fits well with the professional role and the competences of Dutch GPs. However, the subject should not be restricted to the conversation between the patient and the GP. It should become a matter of course in multidisciplinary, patient-centred care, and the subject should be included in information-sharing between professionals. Such conversations should follow the principles of shared-decision making.

When it comes to death and dying in our changing society, patient autonomy is a major topic, and physicians are under pressure to change their attitudes toward a patient-centred approach. Early and ongoing knowledge of the patient's perspectives of both quality of life and all domains of suffering will contribute to such a patient-centred and proactive approach to suffering and to a better understanding of what makes suffering unbearable. In the legal granting of a request for EAS, participation of both the patient and the physician in the final decision is a condition *sine qua non*. Applying the strategies of shared decision-making from the very first end-of-life conversation onward does justice to the importance of relationships in end-of-life decision-making and end-of-life care: it will facilitate a satisfactory outcome regarding the participants' perceptions of a 'good death'.

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# *Chapter 8*

English Summary

Unbearable suffering and euthanasia:  
The patient's perspective

Marianne K. Dees

### **A patient's words**

*'It's in my liver again, and again it's – or I should say, active in my liver and active in my back too, so I have so many symptoms again, and yes, my condition is racing downhill so rapidly that you notice every week that your energy, well what I could do last week I can't do at all anymore. Actually, the only thing I can still do is puzzles. That's the only thing I can do. My garden was a Walhalla. Working in the garden helped me through a very difficult period, but I can't do it anymore.'*

### **Her partner's words**

*'She had still worked in the garden the day before, but now she has said goodbye to the garden. Really, it was very, very poignant and it pierced straight through my soul, but I thought it very good. You know: this is you, that's how you do it. So I walked over to her and I said, "Oh darling, darling, darling, you're saying goodbye, aren't you. Then I held her in my arms and then I let her go again.'*

### **Her GP's words**

*'She decided on her own to stop the chemo in April because it made her feel so really wretched. Hoped that after she stopped she would get some sense of improvement. For example, a little, well, could finish a few things. But she did see that it was deteriorating, that perhaps after that sense of improvement she would get more pain. What was particularly important for this woman was that she was losing control of her own existence.'*

## Introduction

Dutch patients, relatives, and doctors have come a long way since the Postma case in 1973, when a Friesian GP gave her terminally ill mother a deadly injection at her mother's repeated request; and since the Chabot case in 1993, when a woman ended her own life with medicine that was given to her by her treating psychiatrist.

By the Dutch law in effect since 2002, neither euthanasia nor help in committing suicide is a criminal offence provided it is done by a doctor who acts in accordance with the six criteria of due care. The doctor's actions are investigated after the death by one of the regional review committees. Doctors are not obliged to cooperate with a request for euthanasia. In the year 2012, it is expected by the Dutch public and the profession, as represented by the Royal Dutch Medical Association, that a physician who is unwilling to perform euthanasia will refer the requesting patient to another doctor. In 2011, the regional review committees received 3695 reports of euthanasia or assisted suicide. In that year, the committees judged that the physician had not met the requirements of due care in four cases.

The criteria of due care require that the treating physician must:

1. Be convinced that the patient's request is voluntary and well considered
2. Be convinced that the patient is suffering unbearably and hopelessly
3. Inform the patient well about his/her situation and prospects
4. Be convinced, as the patient must also be, that no other reasonable solution is available
5. Consult at least one other independent doctor, who must see the patient and give his/her written opinion about whether the first four criteria have been satisfied
6. Use all due care in terminating the life or assisting in the suicide.

The second requirement of due care, namely, that the physician must be convinced that there is hopelessness and unbearable suffering, is a persistent theme in the broad social, professional, and ethical debates about euthanasia. Especially the term 'unbearable' raises questions. 'Unbearable suffering' with an associated request for euthanasia or assisted suicide is the unique experience of an individual in specific circumstances. The views of the treating physician about life, dying, and death, along with his communication skills, play a major part in deciding about a request for euthanasia. The specially trained independent consultants [Support and Consultation on Euthanasia in the Netherlands (SCEN) physicians] appear to disagree in practice about the extent to which a patient is suffering unbearably. If a regional review committee has questions about the criteria of due care, they are usually about unbearable suffering.

This lack of clarity about what 'unbearable' means has led to the research questions of this thesis:

1. What does the suffering consist of for a patient with an actual request for euthanasia and what makes it unbearable?
2. What, according to the person's closest relative, the attending physician, and the independent consultant, does the suffering of the patient consist of and what makes it unbearable?
3. How is a decision made about a request for euthanasia?

Patients and physicians appear to be able to make a joint decision about implementing euthanasia within the frameworks of legislation and despite the lack of guidance for decision-making and assessing unbearable suffering. How do they do that? We have used the stories of patients, their relatives, and treating physicians to answer our research questions.

We interviewed 41 patients who requested euthanasia or help in committing suicide. Thirty-two of them made a formal request. Twenty of them died after euthanasia or help with suicide. We interviewed 31 families and 28 doctors, and we received 24 consultation reports. The interviews with patients and relatives took place at their homes, and we interviewed the attending physicians in their practices.

## Unbearable suffering

**Chapter 2** gives an overview of the national and international literature about unbearable suffering in the context of a request for euthanasia. This overview shows that there is no generally accepted definition of 'unbearable suffering' in the context of a request for euthanasia. Furthermore, it appears that the term 'unbearable suffering' has medical, psycho-emotional, social, and existential dimensions and that there are many different reasons for euthanasia. Patients, relatives, and healthcare professionals all differ in what they consider reasons for euthanasia.

On the basis of the literature, we define 'unbearable suffering' in the context of a request for euthanasia as a 'profound personal experience caused by an actual or perceived ongoing threat to the integrity or the survival of the person'. There are large differences in the perception of unbearable suffering among patients, relatives, and healthcare professionals. These differences come to the fore in the literature and confirm the importance of qualitative research into the concept of unbearable suffering in the context of a request for euthanasia. Such research should focus on patients with a current request for euthanasia, their relatives, and their healthcare professionals.

**Chapter 3** describes unbearable suffering from the perspective of the patient who has a current request for euthanasia. Analysis of the 31 in-depth interviews revealed that the patients see unbearable suffering as the result of an intensive

process that is rooted in the symptoms resulting from disease or ageing. Elements in the medical, psycho-emotional, social, and existential themes contribute to their suffering. Elements in the existential themes contribute greatly to the experience of unbearability that is always associated with hopelessness. Patients use the term ‘hopeless’ to indicate that the absence of all prospect of improvement is unacceptable to them. Intractable physical symptoms such as fatigue and neurological pain contribute to the perception of unbearable suffering by means of their impact on the quality of life.

The life expectancy of most patients who request euthanasia is limited. Therefore, the treatability of psycho-emotional and existential elements of unbearable suffering are also limited. This emphasises the importance of the early detection of symptoms and negative emotions, fear of future suffering, mental exhaustion, loss of autonomy, loss of quality of life, futility, and feelings that there is nothing left to live for.

This study makes it clear that patients evaluate their suffering in the context of their personal characteristics, their life story, and the interpretation of their existence. As soon as this evaluation calls up strong feelings of hopelessness, they experience their suffering as unbearable. On the basis of these results, we conclude that their suffering is rooted in the symptoms of illness or old age, but especially elements of the existential and psycho-emotional themes determine how much hope many patients have and to what extent patients can bear their suffering.

## Reaching a shared-decision

**Chapter 4** describes the results of the qualitative analysis of the decision-making about a request for euthanasia and makes recommendations for optimising the process as a whole. The analysis of the in-depth interviews with patients, their relatives, and their doctors, along with the reports of independent consultants, showed that a request for euthanasia is perceived as one of the most difficult and most taxing things to deal with in medical practice. Close cooperation between patients, relatives, and doctors is necessary to respectfully come to a joint decision about unbearable suffering. We distinguish five themes in this complex process: (1) sharing viewpoints and values about euthanasia, (2) building a physician–patient relationship that makes joint decision-making possible, (3) compliance with the criteria of due care, (4) the intensive process of preparation and implementation of euthanasia, and (5) the aftercare for the relatives and the physician who performed the euthanasia. The complex process requires an intensive joint effort that is carefully coordinated. It requires the doctor to have high levels of integrity, commitment, communication, insight into family relationships, and professional behaviour. It is important that patients and doctors recognise that they each have a voice in the final decision. A decision about euthanasia can only be understood in



the context of the course of events, the people involved, and the concrete situation. Talking about euthanasia prepares families for the impending death. It turned out that systematic aftercare had not been put in place and that relatives were left with unresolved emotions about the speed of the decision and the unnatural manner of dying.

From this information we conclude that it is important that the treating physician in a palliative care programme take the initiative in a timely way and start a conversation about different viewpoints and values concerning the end of life and euthanasia. The conversation should include the thoughts of both the patient and the physician. This provides time and space to 1) build up the right relationships with patients and relatives, 2) satisfy the criteria of due care, 3) to prepare and implement the euthanasia in detail, and 4) provide aftercare for the relatives.

**Chapter 5** compares the patients' views of unbearable suffering with the views of the GP and the relatives. The description in the independent consultant's report is also compared with the patient's view. We analysed 20 cases in which the patient and the GP agreed that there was unbearable suffering. The elements of unbearable suffering were compared within the medical, psycho-emotional, social, and existential themes.

The comparison showed that, even if a patient and GP agree that there is unbearable suffering, there will still be differences of opinion between the patient, relatives, GP, and independent consultant in the interpretation of unbearable suffering. These differences were particularly evident in the medical, social, and existential themes. The GPs tended to name more medical elements than the patient did. The GP and consultant included elements of the social theme less often in their descriptions of unbearable suffering. This was primarily in regard to 'being a burden' and 'the prospect of having to go to a nursing home'. The relatives' views were very consistent with those of the patient regarding the perception of the existential elements of unbearable suffering. The consultants rarely reported 'nothing left to live for' to the regional review committees and they did not explicitly say from what perspective they described the unbearable suffering. These findings suggest that if the GP is convinced that there is unbearable suffering, it is not obvious that he knows that suffering from the patient's perspective. These results raise the question of how the relative's knowledge of unbearable suffering can contribute to the treating physician's and the consultant's better assessing this suffering.

The results lead us to the conclusion that knowledge about unbearable suffering will increase among treating physicians, consultants, and regional review committees by means of a systematic exploration of the medical, psycho-emotional, social, and existential elements of suffering.



**Chapter 6** describes how linguistic analysis of conversations about the end of life can help improve doctor–patient communication. The literature, field research, and practice all emphasise the importance of adequate communication about the end of life. Spoken language is an essential and accessible part of communication. Our literature survey revealed that discussions with patients, relatives, and professionals about the end of life have hardly been linguistically analysed. We analysed 15 interviews regarding five cases quantitatively (TextStat) and qualitatively (bottom-up method). We selected the modal verbs *must*, *want*, *can*, and *may* for this analysis and investigated how patients, relatives, and treating physicians use them. Then we looked at what their usage of these verbs showed about the interpretation of unbearable suffering and what it showed about the behaviour of the individual doctor. The quantitative analyses showed that the modal verb *can* was used most, usually in the negation ‘can no longer’. This ‘can no longer’ was always about the patient and always compared the present with the past. The verb *must* was used the most by the patient himself and usually concerned what he/she had to do. The verb *may* was not used much, and when it was used, it was about the patient or the relative. The verb *want* was used most by the doctor and usually referred to the patient. The quantitative analyses showed that the doctor with a more paternalistic attitude had a preference for the verb *must* with reference to the patient. The doctor who put the patient’s opinion before his own had a preference for the word *want*.

We conclude from these results that the quantitative linguistic analyses confirm the findings of earlier qualitative analyses about the concept of unbearable suffering. The qualitative bottom-up analysis appears to be a way of gaining insight into the connection of language use to relational aspects of communication. We conclude from this that interdisciplinary research in the medical domain is worthwhile. Further, we believe that linguistic analysis can help optimise doctor–patient communication.

## Recommendations

**Chapter 7** gives a brief introduction to the Dutch history and legal frameworks of euthanasia, after which the qualities, limitations, and main results of this study are summarised and discussed. This chapter closes with recommendations for practice, education, and future research. The core of these recommendations can be summarised as follows.

A timely insight into the needs and expectations of the patient about his life is part of good palliative and end-of-life care. Conversations about these needs and expectations should begin before the patient and his relatives have lost their hopes. Treating physicians should be able to talk openly with patients and relatives about their wishes and expectations about the end-of-life and not let their own norms and values interfere with those of the patient and relatives. In countries where

euthanasia is legal, the question of a possible desire for euthanasia should be part of this conversation.

Continuity of care and trust in the doctor–patient relationship are crucial to the intensive effort to achieve a decision about euthanasia. Given the importance of continuity of care GPs and specialists in the care for the elderly are the preferred physicians to initiate this conversation and to supervise the process. In assessing the suffering of a patient with a request for euthanasia, it is advisable to systematically map out the medical, psycho-emotional, social, and existential aspects of suffering in good time and to identify aspects of the patient’s personality, life, and interpretation of existence that makes this suffering unbearable.







# *Chapter 9*

Nederlandse samenvatting

Ondraaglijk lijden en euthanasie:  
De beleving van de patiënt centraal

Marianne K. Dees

### **Citaat van een patiënte**

*'het zit weer in mijn lever en het zit weer, tenminste actief in de lever en ook actief, in mijn rug, dus ik heb nu weer zoveel klachten, en ik ja, ga nu zo hard hollend achteruit, dat je gewoon merkt dat je per week je energie verliest, wat ik vorige week nog kon dat kan ik nu helemaal niet meer, eigenlijk het enige wat ik nog kan is puzzelen, dat is het enige wat ik nog kan, mijn tuin was een walhalla, om in de tuin te werken heeft mij door een hele moeilijke periode geholpen maar dat kan ik niet meer.'*

### **Citaat van haar naaste**

*'ze heeft de dag van te voren nog in de tuin gewerkt, ze heeft afscheid genomen van de tuin, echt het was heel, heel ontroerend en het ging dwars door mijn ziel heen maar ik vond het wel heel goed weet je, dit ben jij, zo doe jij dat, dus ik ben toen naar haar toe gelopen en toen heb ik gezegd ach schatje, schatje, schatje, je bent afscheid aan het nemen hè, toen heb ik haar vastgehouden en toen heb ik haar weer losgelaten.'*

### **Citaat van haar huisarts**

*'ze is in april op eigen initiatief gestopt met de chemo omdat ze zich daar heel beroerd door voelde. Hoopte dat ze daar na het stoppen een soort opleving zou krijgen, dat ze bijvoorbeeld een beetje, ja een aantal dingen kon afronden en ja zag wel in dat het een aflopende zaak was, dat ze misschien na die opleving ook meer pijn zou krijgen. Wat met name bij deze vrouw een rol speelde is dat ze d'r regie in eigen bestaan kwijt aan het raken was.'*



## Inleiding

Nederlandse patiënten, naasten en artsen hebben een lange weg afgelegd sinds de zaak Postma in 1973 waarin een Friese huisarts haar terminaal zieke moeder op diens herhaaldelijk verzoek een dodelijke injectie toediende en sinds de zaak Chabot in 1993 waarin een vrouw haar leven beëindigde door het innemen van medicijnen die haar werden aangereikt door haar behandelend psychiater.

Sinds 2002 is in Nederland wettelijk geregeld dat euthanasie en hulp bij zelfdoding niet strafbaar zijn mits deze wordt uitgevoerd door een arts. De arts moet aan zes zorgvuldigheidseisen voldoen en zijn handelen wordt na de uitvoering getoetst door één van de regionale toetsingscommissies. Artsen zijn niet verplicht mee te werken aan een verzoek tot euthanasie. Anno 2012 verwacht het Nederlandse publiek, en de beroepsgroep bij monde van de KNMG wel dat een arts die geen euthanasie wil uitvoeren doorverwijst naar een andere arts. In 2011 hebben de regionale toetsingscommissies 3695 meldingen van levensbeëindiging op verzoek of hulp bij zelfdoding ontvangen. In dat jaar kwamen de commissies vier keer tot het oordeel dat de arts niet aan de zorgvuldigheidseisen had voldaan.

De zorgvuldigheidseisen houden in dat de arts:

1. De overtuiging heeft gekregen dat er sprake was van een vrijwillig en weloverwogen verzoek van de patiënt
2. De overtuiging heeft gekregen dat er sprake was van uitzichtloos en ondraaglijk lijden van de patiënt
3. De patiënt heeft voorgelicht over de situatie waarin deze zich bevond en over diens
4. vooruitzichten
5. Met de patiënt tot de overtuiging is gekomen dat er voor de situatie waarin deze zich bevond geen redelijke andere oplossing was
6. Ten minste één andere, onafhankelijke arts heeft geraadpleegd, die de patiënt heeft gezien en schriftelijk zijn oordeel heeft gegeven over de eerste vier zorgvuldigheidseisen
7. De levensbeëindiging of hulp bij zelfdoding medisch zorgvuldig heeft uitgevoerd.

De tweede zorgvuldigheidseis waarbij de arts de overtuiging moet hebben dat er sprake is van uitzichtloos en ondraaglijk lijden is een blijvend thema in de brede maatschappelijke, professionele en ethische discussies rondom euthanasie. Vooral de term ‘ondraaglijk’ roept vragen op. ‘Ondraaglijk lijden’ met een daaraan gekoppeld verzoek tot euthanasie of hulp bij zelfdoding, is een unieke beleving van een individu in specifieke omstandigheden. De opvattingen van de behandelend arts over leven, sterven en dood en diens communicatieve vaardigheden, spelen tijdens de besluitvorming bij een verzoek tot euthanasie een grote rol. De speciaal daartoe opgeleide onafhankelijke consulenten (SCEN-artsen) blijken in de praktijk

van mening te verschillen over de mate waarin een patiënt ondraaglijk lijdt. Als een regionale toetsingscommissie vragen heeft over de zorgvuldigheidseisen gaat het meestal over ‘ondraaglijk lijden’.

Deze onduidelijkheid over wat ‘ondraaglijk’ betekent heeft geleid tot de onderzoeksvragen van dit proefschrift:

- Waaruit bestaat het lijden van een patiënt met een actueel verzoek tot euthanasie en wat maakt het ondraaglijk?
- Waaruit bestaat volgens de naaste, de behandelend arts en de onafhankelijke consulent het lijden van deze patiënt en wat maakt het ondraaglijk?
- Hoe verloopt de besluitvorming bij een verzoek tot euthanasie?

Patiënten en artsen blijken in staat te zijn om, binnen de kaders van de wetgeving en ondanks het ontbreken van richtlijnen over besluitvorming en beoordeling van ondraaglijk lijden, tot een gezamenlijk besluit te komen over de uitvoering van euthanasie. Hoe doen zij dat? We hebben de verhalen van patiënten, hun naasten en behandelend artsen gebruikt om een antwoord te geven op de onderzoeksvragen.

We hebben 41 patiënten, met een verzoek tot euthanasie of hulp bij zelfdoding geïnterviewd. Tweeëndertig van hen hadden een actueel verzoek. Twintig van hen overleden na euthanasie of hulp bij zelfdoding. We interviewden 31 naasten; 28 behandelend artsen en kregen de beschikking over 24 consultatie rapporten. De interviews met de patiënten en naasten vonden bij hen thuis plaats; met de behandeld arts in hun praktijk.

## Ondraaglijk lijden

In **hoofdstuk 2** geven we een overzicht van de nationale en internationale literatuur over ondraaglijk lijden in de context van een verzoek tot euthanasie. Uit dit overzicht blijkt dat er geen algemeen geaccepteerde definitie van ‘ondraaglijk lijden’ in de context van een verzoek tot euthanasie is. Verder komt naar voren dat het begrip ‘ondraaglijk lijden’ een medische, psycho-emotionele, sociale en existentiële dimensie bevat en dat er veel verschillende redenen voor euthanasie bestaan. Patiënten, naasten en professionals in de zorg, verschillen onderling in wat zij redenen voor euthanasie vinden.

Op grond van de literatuur definiëren we ‘ondraaglijk lijden’ in de context van een verzoek tot euthanasie als een ‘diepgaande persoonlijke beleving die veroorzaakt wordt door een werkelijke of ervaren aanhoudende bedreiging van de integriteit of het voortbestaan van de persoon’. De grote verschillen in visie op ondraaglijk lijden tussen patiënten, naasten en professionals in de zorg, die uit de literatuur naar voren komen ondersteunen het belang van kwalitatief onderzoek naar het begrip ‘ondraaglijk lijden’ in de context van een verzoek tot euthanasie. Dergelijk

onderzoek moet zich richten op patiënten met een actueel verzoek tot euthanasie, hun naasten en hun professionals in de zorg.

In **hoofdstuk 3** wordt ‘ondraaglijk lijden’ beschreven vanuit het perspectief van de patiënt die een actueel verzoek tot euthanasie heeft. Uit analyse van de 31 diepte interviews met patiënten bleek dat zij ‘ondraaglijk lijden’ zien als het resultaat van een intensief proces dat zijn oorsprong vindt in de symptomen die voortkomen uit ziekte of veroudering. Elementen uit het medische, het psycho-emotionele, het sociale en het existentiële thema dragen bij aan hun lijden. Elementen uit het existentiële thema dragen in sterke mate bij aan het ervaren van ondraaglijkheid waarbij uitzichtloosheid altijd wordt genoemd. Patiënten gebruiken de term uitzichtloos om aan te geven dat het ontbreken van elk vooruitzicht op verbetering voor hen onaanvaardbaar is. Onbehandelbare fysieke klachten zoals vermoeidheid en neurologische pijn dragen bij aan de beleving van ‘ondraaglijk lijden’ door hun effect op de kwaliteit van leven. Voor de meeste patiënten die een verzoek tot euthanasie doen is de levensverwachting beperkt. Hierdoor is ook de behandelbaarheid van psycho-emotionele en existentiële elementen van ondraaglijk lijden beperkt. Dit benadrukt het belang van vroege opsporing van klachten als negatieve emoties, angst voor toekomstig lijden, geestelijke uitputting, verlies van autonomie, verlies van kwaliteit van leven, zinloosheid en klaar met leven-gevoelens.

Dit onderzoek maakt duidelijk dat patiënten hun lijden evalueren in de context van hun persoonskenmerken, hun levensverhaal, en de invulling van hun bestaan. Zodra deze evaluatie sterke gevoelens van uitzichtloosheid oproept, beleven zij hun lijden als ondraaglijk. Op grond van deze resultaten komen we tot de conclusie dat lijden wortelt in de symptomen van ziekte of ouderdom, maar dat vooral elementen uit het existentiële en het psycho-emotionele thema bepalen hoeveel hoop patiënten hebben en in hoeverre patiënten in staat zijn hun lijden te dragen.

## **Samen tot een besluit komen**

**hoofdstuk 4** worden de resultaten beschreven van de kwalitatieve analyse van de besluitvorming bij een verzoek tot euthanasie en doen we aanbevelingen voor een optimalisering van het besluitvormingsproces. Uit de analyse van de diepte interviews met patiënten, hun naasten, hun behandelend artsen en van de verslagen van onafhankelijke consulenten kwam naar voren dat een verzoek tot euthanasie wordt ervaren als één van de moeilijkste en meest belastende zaken in de medische praktijk. Er is een intensieve samenwerking tussen patiënten, naasten en artsen nodig om op een respectvolle manier tot een gezamenlijk besluit over ‘ondraaglijk lijden’ te komen. Binnen dit complexe proces kunnen vijf thema’s worden onderscheiden: 1) het delen van visies en normen en waarden over euthanasie, 2) het opbouwen van een arts-patiënt relatie die een gezamenlijk besluitvormingsproces mogelijk

maak, 3) het voldoen aan de zorgvuldigheidscriteria, 4) het intensieve proces van voorbereiding en uitvoering van euthanasie, 5) de nazorg voor de naasten en de arts die de euthanasie heeft uitgevoerd. Dit complexe proces vereist een intensief gezamenlijk traject waarbinnen zorgvuldige afstemming moet plaatsvinden. Het vraagt van de arts een hoog niveau van oprechtheid, betrokkenheid, communicatie, inzicht in familieverhoudingen en professioneel gedrag. Het is belangrijk dat patiënt en arts onderkennen dat ze allebei een stem hebben in het uiteindelijke besluit. Besluitvorming over euthanasie is alleen te begrijpen in de context van de loop der gebeurtenissen, de betrokken personen en de concrete situatie. Praten over euthanasie bereidt naasten voor op de naderende dood. Uit ons onderzoek bleek dat niet voorzien werd in systematische nazorg en dat naasten achterbleven met onverwerkte emoties over de snelheid van het besluitvormingsproces en de onnatuurlijke manier van sterven.

Uit het bovenstaande concluderen we dat het belangrijk is dat de behandelend arts bij een palliatief zorgtraject tijdig het initiatief neemt om een gesprek te beginnen waarin hij de verschillende visies en normen en waarden over het levenseinde en euthanasie, van de patiënt en van hem zelf, exploreert en deelt. Dit faciliteert tijd en ruimte om 1) de juiste relaties op te kunnen bouwen met patiënt en naasten, 2) aan de zorgvuldigheidscriteria te voldoen, 3) de euthanasie in detail te kunnen voorbereiden en uitvoeren en 4) nazorg aan de naasten te kunnen geven.

In **hoofdstuk 5** wordt de visie van patiënten op ondraaglijk lijden vergeleken met die van de huisarts en de naaste(n) en met de omschrijving in het verslag van de onafhankelijke consulent. We analyseerden 20 casussen waarin zowel de patiënt zelf als de huisarts het er over eens waren dat er sprake was van ondraaglijk lijden. De genoemde elementen van ondraaglijk lijden werden met elkaar vergeleken binnen het medische, het psycho-emotionele, het sociale en het existentiële thema. Uit deze vergelijking kwam naar voren dat als patiënt en huisarts het er over eens zijn dat er sprake is van ondraaglijk lijden, er toch verschillen zijn tussen patiënt, naaste(n), huisarts en onafhankelijke consulent wat betreft de interpretatie van ‘ondraaglijk lijden’. Deze verschillen kwamen vooral naar voren in het medische, sociale en existentiële thema. Huisartsen hadden de neiging meer medische elementen te noemen dan hun patiënt. Huisarts en consulent betrokken elementen uit het sociale thema minder in hun beschrijving van ondraaglijk lijden. Dit betrof vooral het ‘tot last zijn’ en ‘het vooruitzicht naar een verpleeghuis te moeten’. Naasten kwamen sterk met de patiënt overeen wat betreft de beleving van de existentiële elementen van ondraaglijk lijden. Daarnaast bleek dat consulenten ‘het klaar zijn met het leven’ zelden aan de regionale toetsingscommissies rapporteerden en meestal niet expliciet benoemden vanuit welk perspectief zij ondraaglijk lijden beschreven. Deze bevindingen suggereren dat als de huisarts tot de overtuiging is gekomen dat er sprake is van ondraaglijk lijden, het niet vanzelfsprekend is dat hij het patiënten perspectief van dat lijden kent. Deze resultaten roepen tevens de

vraag op hoe de kennis van naaste(n) over het ondraaglijk lijden kan bijdragen aan een betere inschatting van dit lijden door behandelend arts en consulent.

Op grond van deze resultaten komen we tot de conclusie dat door een systematische exploratie van de medische, psycho-emotionele, sociale en existentiële elementen van lijden, de kennis over ondraaglijk lijden bij behandelend arts, consulent en regionale toetsingscommissie zal toenemen. Een completere kennis van het perspectief van de patiënt op ondraaglijk lijden zal de transparantie van de besluitvorming en de beoordeling van de zorgvuldigheidseisen doen toenemen.

In **hoofdstuk 6** wordt beschreven hoe taalkundige analyse van gesprekken over het levenseinde kunnen bijdragen aan het verbeteren van de arts-patiënt communicatie. Literatuur, veldonderzoek en de dagelijkse praktijk benadrukken het belang van adequate communicatie als het gaat over het levenseinde. De gesproken taal is een essentieel en toegankelijk onderdeel van communicatie. Uit het literatuuronderzoek bleek dat gesprekken met patiënten, naasten en professionals over het levenseinde nog nauwelijks taalkundig zijn geanalyseerd. Wij analyseerden 15 interviews, betreffende vijf casussen, kwantitatief (TextStat) en kwalitatief (bottom-up methode). Voor deze analyse werden de modale werkwoorden: 1) moeten, 2) willen, 3) kunnen, 4) mogen geselecteerd. We onderzochten hoe patiënt, naaste en behandelend arts de modale werkwoorden *willen*, *moeten*, *kunnen* en *mogen* gebruikten. Daarna werd bekeken wat het gebruik van deze werkwoorden lieten zien over de interpretatie van ‘ondraaglijk lijden’. Als laatste werd gekeken wat het gebruik van deze werkwoorden onthulde over het gedrag van de individuele arts. Uit de kwantitatieve analyses bleek dat het modale werkwoord ‘kunnen’ het meest werd gebruikt, meestal in combinatie met de ontkenning ‘niet meer kunnen’. Het ‘niet meer kunnen’ ging altijd over de patiënt en het betrof dan de vergelijking van het heden met het verleden. Het werkwoord ‘moeten’ werd het meest gebruikt door de patiënt zelf en dan ging het vooral over wat hij moest doen. Het werkwoord ‘mogen’ werd weinig gebruikt en als het gebruikt werd ging het over de patiënt of de naaste. Het woord ‘willen’ werd het meest gebruikt door de arts en dit had in de meeste situaties betrekking op de patiënt. Uit de kwantitatieve analyses kwam naar voren dat de arts met een meer paternaliserende houding een voorkeur had voor het gebruik van het werkwoord *moeten* met betrekking tot de patiënt. De arts die zijn eigen mening ondergeschikt maakte aan die van de patiënt had een voorkeur voor het woord gebruik van het woord *willen*.

Uit bovenstaande resultaten kunnen we concluderen dat de kwantitatieve taalkundige analyses de bevindingen van de eerdere kwalitatieve analyses van het concept ‘ondraaglijk lijden’ ondersteunen. De kwalitatieve taalkundige ‘bottom-up’ analyse blijkt een manier om inzicht te krijgen in de samenhang van het taalgebruik met relationele aspecten binnen de communicatie. Hieruit concluderen we dat het zinvol is om binnen het medische domein interdisciplinair onderzoek te

doen. Verder zijn we van mening dat taalkundige analyse een bijdrage kan leveren aan optimalisering van de arts-patiënt communicatie.

## Aanbevelingen

In **hoofdstuk 7** worden na een korte inleiding over de historische en wettelijke kaders van euthanasie in Nederland, de kwaliteiten, de beperkingen en de belangrijkste resultaten van deze studie samengevat en bediscussieerd. Dit hoofdstuk sluit af met aanbevelingen voor praktijk, onderwijs en toekomstig onderzoek. De kern van deze aanbevelingen kan als volgt kort worden samengevat. Een tijdig inzicht in de wensen en verwachtingen van de patiënt over zijn levenseinde maakt deel uit van goede palliatieve en terminale zorg. Dit gesprek behoort te beginnen voordat patiënt en naaste(n) de hoop op genezing hebben verloren. Behandelend artsen moeten in staat zijn open met patiënten en naasten over hun wensen en verwachtingen aangaande het levenseinde te praten zonder eigen normen en waarden aan de patiënt en naaste(n) op te dringen. In landen waar euthanasie gelegaliseerd is hoort de vraag naar een mogelijke wens tot euthanasie in dat gesprek thuis. Continuïteit van zorg en vertrouwen binnen de arts-patiënt relatie zijn cruciaal bij het intensieve traject naar een besluit tot euthanasie. Huisarts of de specialist ouderenzorg zijn de eerst aangewezenen om dit gesprek te voeren en het proces te begeleiden. Bij het beoordelen van het lijden van een patiënt met een verzoek tot euthanasie verdient het aanbeveling om tijdig en systematisch de medische, psycho-emotionele, sociale en existentiële aspecten van het lijden in kaart te brengen en na te gaan welke aspecten van de persoonlijkheid, van het levensverhaal en van de invulling van het bestaan dit lijden ondraaglijk maken.





## Promoveren is een voorrecht

In mijn dankwoord wil ik in de eerste plaats stil staan bij de patiënten die bereid waren om openhartig met mij te spreken over hun lijden en hun verzoek tot euthanasie, op een moment dat hen nog slechts korte tijd restte. Mijn dank is ook gericht aan de naasten die mij gastvrij ontvingen in een voor hen emotionele periode en mij vertelden over hun beleving van het lijden van hun dierbare en over de besluitvorming rondom het sterven. De inzet van de SCEN-artsen en de behandelend artsen om patiënten te vragen deel te nemen dit onderzoek is van cruciaal belang geweest voor het tot stand komen van dit proefschrift.

## Het promotieteam

Myrra Vernooij-Dassen, in 2006 kwam ik bij je met mijn A-4tje en de vraag *“hoe pak ik het aan om te promoveren”*. Binnen 10 minuten was het geregeld. Ik ging de deur uit met jou als copromotor en Chris van Weel als promotor. Deze rollen zijn inmiddels omgedraaid. Samen waren we het eens dat we met Wim Dekkers als ethicus en Kris Vissers als hoogleraar palliatieve zorg een stevige promotiecommissie zouden hebben. Terugkijkend op de afgelopen jaren kan ik niet anders dan concluderen dat het een vruchtbare samenwerking is gebleken. Jij als de leermeester en ik als de gezelschap. De manier waarop je me een planning liet maken was even slikken maar ik doe nu hetzelfde bij mijn studenten en het werkt. Jouw kennis en ervaring over kwalitatief onderzoek vielen bij mij in vruchtbare aarde en voor ik het wist was ik een groep startende promovendi voor deze onderzoeksmethode aan het enthousiasmeren. De wijze waarop je bij het schrijven van de artikelen de lat telkens net iets hoger legde heeft ervoor gezorgd dat ik in mijn rol als onderzoeker heb kunnen groeien. En dan waren er soms ineens die bijzondere momenten waarop wij als Myrra en Marianne deelden wat ons bezig hield: *‘ik heb ze ervaren als pareltjes’*. Myrra, ik wil je danken voor jouw bijzondere bijdrage aan mijn verhaal.

Chris van Weel, ik vraag me nog steeds af hoe je er bij kwam om ‘ja’ te zeggen toen Myrra je die bewuste dag belde met de vraag of je promotor wilde zijn van een externe promovenda die je nog nooit gezien had. Maar misschien zit in die herkenning van dat wat kans van slagen heeft wel de essentie van jouw bijdrage aan dit verhaal. Het uitgebalanceerde evenwicht dat jij wist aan te brengen tussen een compliment, opbouwende kritiek en duwtje in de rug komt tot uiting in het volgende citaat *“grote lijn prima, mag korter en krachtiger, tekstueel. Is dit een goede basis voor een artikel waarin je je onderzoek samenvat (voor na de promotie?!)”*. Deze aanpak maakte dat ik altijd, vanaf jouw verrassend snelle reactie uit Hongkong op het concept van mijn eerste artikel, uitzag naar jouw feedback. Een gedenkwaardig leermoment was jouw feedback op mijn repliek op een van mijn artikelen *“Looks very good, be a bit more kind to the second reviewer”*. Ik kijk nu al met weemoed terug naar die ontspannen besprekingen met het gehele promotieteam op jouw kamer. Daar mocht ik onderdeel zijn van een

proces waarbij verschillende visies en referentiekaders een product leverden dat meer was dan de som der samenstellende delen.

Kris Vissers, voor mij hoorde jij als hoogleraar palliatieve zorg thuis in dit promotietraject. Inmiddels zijn we het eens dat euthanasie een plek heeft in de besluitvorming rondom het levenseinde en daarmee in de zorg voor patiënten die zich in de palliatieve fase van hun ziekte bevinden. Het was mij een genoegen met je te mogen sparren over de schema's, de concepten en de theorieën die de resultaten van mijn onderzoek bij jou opriepen. Ze prikkelden me om achteraf tot op de bodem uit te zoeken waarom ik het wel of niet met je eens was om ze daarna in een andere context te benutten. Een van jouw vernieuwende ideeën zien we terug in het artikel dat wij samen met twee linguïsten van de Universiteit van Gent schreven. Ons verhaal is wat mij betreft nog niet klaar. We zullen elkaar blijven ontmoeten op de overgangen tussen de eerste en de tweede lijn in onze gezamenlijke betrokkenheid bij de verbetering van de kwaliteit van leven van patiënten en hun naasten die te maken hebben met een levensbedreigende aandoening.

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## The extra input

Glyn Elwyn, it was a great stimulus when you called my data unique and of importance. Although *“strange things happen overseas”*, for me your experience as an expert in shared-decision-making, was extremely helpful to come to an understanding of the process of decision-making in euthanasia. Your scientific knowledge facilitated the recognition of categories and themes within the qualitative data and hypothesizing about decision-making in a request for euthanasia.

Sylvain Dieltjens en Priscilla Heynderickx, de taalkundige analyse van mijn gesprekken met patiënten, naasten en behandelend artsen was voor mij een sprankelende en vernieuwende ervaring. Onze ontmoetingen als wetenschappers met verschillende referentiekaders prikkelden mijn fantasie en opende voor mij nieuwe gezichtspunten. Ik hoop dat we in de toekomst onze samenwerking verder

kunnen uitbreiden.

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Marloes van den Sigtenhorst, een beter tweede lezer van mijn transcripten had ik me niet kunnen wensen.

Sylvia van Roosmalen, jouw betrouwbare Engelse editing is van onschatbare waarde gebleken.

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## **De ondersteuning**

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## Curriculum Vitae

De auteur van dit proefschrift werd op 14 september 1958 geboren te Goes als Marianne Karin Dees, oudste dochter van Krin Dees en Huigje van de Erve. De eerste 12 jaar van haar leven woonde zij op boerderij ‘Landmanslust’ in de Willem Anna polder te Kapelle-Biezelinge. Gedurende haar middelbare schoolperiode woonde zij in Arnhem. Tijdens de brugklas bij de familie Schellevis en daarna bij mevrouw Rothuizen –Touw. In 1977 slaagde zij voor haar Gymnasium B diploma aan het Christelijk Lyceum.

Na het behalen van haar propedeuse Geologie werd zij in 1979 ingeloot voor de studie geneeskunde aan de Rijks Universiteit Utrecht. Tijdens deze studie werkte zij achtereenvolgend als studenten-assistent ‘studievaardigheden’ en ‘communicatie-en-interview training’. Na het behalen van het artsexamen in 1985 was zij anderhalf jaar werkzaam als arts-assistent psychiatrie in de voormalige Rijks Psychiatrische inrichting te Eindhoven. Zij verwierf een opleidingsplaats psychiatrie aan de Katholieke Universiteit Nijmegen met een promotieonderzoek op het gebied van de ziekte van Alzheimer. Na een jaar besloot zij de bakens te verzetten. Zij werkte enige tijd als arts-assistent psychiatrie in ziekenhuis Rijnstaete te Arnhem en besloot huisarts te worden. Zo werd zij in 1988 toegelaten tot de tweejarige beroepsopleiding tot huisarts aan de Rijks Universiteit Utrecht. Vanaf 1991 tot op de dag van vandaag is zij werkzaam als huisarts in ‘De Schakel’ in de wijk Dukenburg te Nijmegen.

In 2000 besloot zij haar horizon te verbreden en nam zij deel aan de postacademische cursus ‘ethiek in de huisartsenpraktijk’, waarna ze in 2001 de opleiding tot SCEN-arts volgde. Tot op heden is zij actief als SCEN-arts in de regio Nijmegen en omgeving. Sinds kort is zij als docent verbonden aan de KNMG Opleiding tot SCEN-arts. Tevens werd zij in dat jaar huisartsen opleider aan de Voortgezette Opleiding tot Huisarts aan het UMCN St Radboud. De drie daaropvolgende jaren breidde zij haar competenties uit als huisartsen groepsbegeleider. Vanaf 2005 richtte zij zich op de voorbereidingen van haar proefschrift. Dit resulteerde in een KWF subsidie waarmee zij in 2007 als externe promovendus kon starten aan de UMCN St Radboud met het onderzoek wat leidde tot het huidige proefschrift. Recent werd zij aangesteld als postdoc aan het UMC St Radboud bij het onderzoek ‘stoppen met medicatie in de terminale fase’.

Marianne is niet alleen huisarts, SCEN-arts en onderzoeker maar vooral ook trotse moeder van Frederike (1990), Wieland (1992) en Konradin (1995).



