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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.

Keywords

Decision-making, shared, qualitative research, euthanasia, end-of-life care, advanced health care planning, physician-patient relation

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

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legally performed on condition that six rules of due care are adhered to¹ (Box 1) is carried out by a physician and reported to one of the five Regional Review Committees.² 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.³ The legal framework increased the transparency on decision-making in EAS^{4–7} 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 themselves⁶ and were not influenced by others.^{8,9} It was found that the assessment of a request being voluntary and well considered was sometimes complicated,¹⁰ and differences in views on unbearable suffering and hopelessness between patients and attending physicians were important reasons for refusal of a request.^{11,12} It became evident that while some physicians hold the opinion that palliative care was as an alternative for EAS,^{13–15} others found that in three-quarters of the requests, there were no palliative options left to diminish unbearable suffering.¹⁶ 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 shared decision-making (SDM) based on choice, option and decision-talk as described by Elwyn et al.¹⁷ as the best possible approach to deal with the underlying complexities. SDM respects patient autonomy and promotes patient engagement.^{18,19} 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.^{20–22} SDM is not (yet) widely implemented.²³ However, Dutch physicians have managed to come to shared-decisions with patients about EAS requests.

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 Code⁵ 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
 - Give his/her written opinion of the criteria for due care, referred to in parts a to d inclusive
- f. Use all due care in terminating the life or assisting in the suicide

We can profit from their experiences and, in line with Schön's *Reflection in action*,²⁴ 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'.²⁵ A Support and Consultation for Euthanasia (SCEN) specialist is an independent doctor trained to provide SCEN in the Netherlands.

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.^{26,27} 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,²⁸ serial interview study²⁹ 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 and 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.^{30,31} We avoided using preset categories and explored the data as a whole.^{32,33} Two researchers (M.D. and M.S.) independently coded data for five clusters of participants (patient, relative, physician and consultant). The codes were descriptive at the level of participant statements. Next, M.D. and M.S. compared codes and discussed them with a third researcher (M.V.). They agreed on code modifications, mergers and additions and developed a revised coding scheme. M.D. and M.S. 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.

M.D. and M.S. 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 (C.W. and M.D.), a sociologist (M.V.), an ethicist (W.D.) and a palliative care specialist (K.V.). M.D. then reapplied the thematic structure to the data. The peer group, joined by (G.E.), expert on shared decision-making, considered whether the practice described by the participants could be compared to the approach known as shared decision-making.²³ M.D. proposed an optimal process for decision-making in EAS on the basis of the analysis (Figure 1).

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

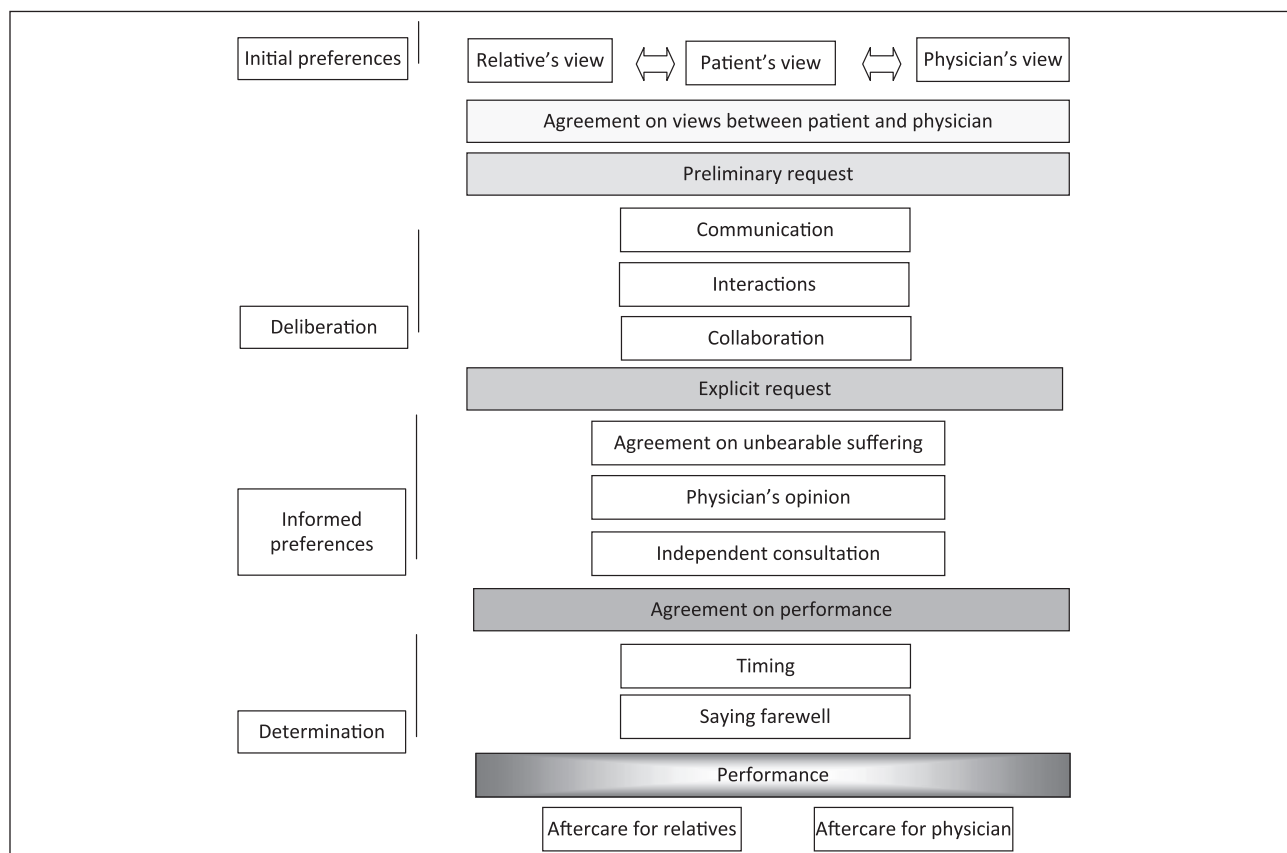


Figure 1. A model for distributed, shared decision-making in euthanasia and physician-assisted suicide.

basis for EAS by the Dutch Supreme Court.³⁴ 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.³⁵ 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*

Table 1. Participant characteristics in cases where patients explicitly requested EAS.

Patient's characteristics					
Gender	Diagnoses (number)		Age in years	Number refused	Reason for refusal
15 males	Cancer (7), heart failure (1), degenerative neurological disease (4), psychiatric disease (3)		32–96	5	Opinion about suffering, competence, treatment options
17 females	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 males	18 GP 1 elderly care 1 psychiatry	3 1	41–64 (55)	Once in 3 years	
8 females	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 males	5 husbands		52–79	2–24	
	5 sons		31–52	1–2	
	1 son-in-law		62	16	
	1 nephew		40	0	
17 females	7 wives		49–78	24	
	2 sisters		56–60	4–8	
	7 daughters		26–61	1–6	
	1 granddaughters		27	1	
Independent consultants' characteristics					
Gender	Specialisation		Age in years		
16 males	11 GP ^a 1 anaesthesiology 3 elderly care 1 tropical care		49–61 (54)		
7 females	4 GP 3 elderly care		48–58 (54)		

EAS: euthanasia and physician-assisted suicide; SCEN: Support and Consultation for Euthanasia; GP: general practitioner.

^aOne was not a SCEN consultant.

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

Table 2. Themes, categories, and codes about decision-making when patients explicitly requested EAS.

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 and 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 and tries to find a colleague with a positive view.
		Not prepared to assist in dying	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 and considers alternatives for ending his own life.
	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 and lacks knowledge about EAS.
Building relationships	Communication	Opinion of EAS is negative	Stagnation of decision-making.
		Positive influences	Recurrent, profound, open and space for feelings.
	Collaboration	Negative influences	Physician: promotes tranquillity, names his own boundaries, helps patient organise thoughts and express emotions and understands patient's unbearable suffering. Patient: communicates explicitly about wish, can make others understand unbearability and involves loved ones.
			Physician: shows no empathy, communicates only medical aspects, attempts to convince patient that suffering is not unbearable, talks to relatives instead of patient and feels pressured.
		Effective	Patient does not: easily talk about feelings, experience open communication and get a chance to make his own choices.
Patient-physician relation	Patient-physician relation	Positive characteristics	Patient: takes initiative for talks about perspectives, the request for EAS and the request for performance.
			Patient and physician together: make decisions, discuss the rules of due care and inform involved parties.
			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 and wants to be absolutely sure that the patient wants performance.
			Patient: incomplete knowledge about lack of prospects and lawful EAS.
			Physician: incomplete knowledge about lawful EAS, sticks to continuation treatment, insists on palliative sedation as an alternative for EAS and sticks to an authoritative or paternalistic role.
			Knowing each other, respecting each other, feelings of sympathy and acceptance of differences in opinion.
			Patient trusts physician.

(continued)

Table 2. (Continued)

Themes	Categories	Subcategories	Codes
Fulfilment of rules of due care in daily practice	Patient–relative relation	Negative characteristics	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 and is able to brush aside negative feeling towards patient.
		Positive characteristics	Physician: opinion about patient's personality characteristics is negative and attitude is authoritative. Involvement, respect, openness and attention to saying farewell.
		Negative characteristics	Supports patient with preparations and alternatives in case request is refused.
		Positive characteristics	Not respecting patient's views.
	Relative–physician relation	Positive characteristics	Trusts physician, values dedication and support of physician and understands burden on physician.
		Negative characteristics	Lack of knowledge about legal EAS, pressuring physician, demands a SCEN consultation, expects physician to perform EAS without reporting, differences in view of unbearability and considers finding another physician.
	Influences on perception of unbearable suffering		Visibility, understandability, subjectivity and 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.
			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 and psychiatric diagnosis. Optimal palliative treatment. Presence of medical diagnosis, terminal disease, depression, physician's incomplete knowledge of legal possibilities and fear for prosecution.
	Independent consultant		Consultation brings about tension for patient and relative.
			Roles: consultation, support, second opinion and expert. Performance: promised before consultation, despite consultant's negative opinion.
Performance	Timing Saying farewell Performance		Request for performance and performance day.
			People involved informed, rituals and saying goodbye. Method, determination of patient and physician is in charge.
Aftercare	Relative's reflections		Need of time and space. Difficulties accepting illness, request and speed.
			Death on appointment is bizarre. Unnatural way to say farewell. Emotional burden, taboo by environment. Eventually looking back with positive feelings.
	Physician's reflections		Importance of follow-up (interview as chance to reflect). 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; SCEN: Support and Consultation for Euthanasia.

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'.*

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'.*

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 'unbearable suffering'.^{36,37} 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'.²⁴ 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.^{38,39} 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.^{40,41} We found, in agreement with earlier research,⁴² 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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References

1. Euthanasia, the Netherlands new rules. Documentation | 8 April 2002, http://english.minvws.nl/en/folders/ibe/euthanasia_the_netherlands_new_rules.asp (accessed November 2011).
2. Regional euthanasia review committees. *Annual report 2010*. <http://www.euthanasiecommissie.nl/overdetoetsingscommissies/jaarverslag/> (accessed November 2011).
3. De Haan J. The new Dutch law on euthanasia. *Med Law Rev* 2002; 10: 57–75.
4. Abramson R. A dying patient: the question of euthanasia. *Int J Psychiatry Med* 1975; 6: 431–454.
5. Van der Arend A. An ethical perspective on euthanasia and assisted suicide in the Netherlands from a nursing point of view. *Nurs Ethics* 1998; 5: 307–318.
6. Borgsteede S, Deliëns L, Graafland-Riedstra C, et al. Communication about euthanasia in general practice: opinions and experiences of patients and their general practitioners. *Patient Educ Couns* 2007; 66: 156–161.
7. Von Gunten C, Ferris F and Emanuel L. The patient-physician relationship. Ensuring competency in end-of-life care: communication and relational skills. *JAMA* 2000; 284(23): 3051–3057.
8. Balint J. Decisions at the end of life. *Croat Med J* 2000; 41: 144–149.
9. Carlson B, Simopolous N, Goy E, et al. Oregon hospice chaplains' experiences with patients requesting physician-assisted suicide. *J Palliat Med* 2005; 8: 1160–1166.
10. Buiting H, Gevers J, Rietjens J, et al. Dutch criteria of due care for physician-assisted dying in medical practice: a physician perspective. *J Med Ethics* 2008; 34: e12.
11. Jansen-Van der Weide M, Onwuteaka-Philipsen B and Van der Wal G. Granted, undecided, withdrawn, and refused requests for euthanasia and physician-assisted suicide. *Arch Intern Med* 2005; 165: 1698–1704.
12. Onwuteaka-Philipsen B, Jansen-Van der Weide M and Van der Wal G. [Granted, undecided, withdrawn and refused requests for euthanasia and physician-assisted suicide in the Netherlands; 2000–2002]. *Ned Tijdschr Geneesk* 2006; 150(5): 249–254.
13. Georges J, The A, Onwuteaka-Philipsen B, et al. Dealing with requests for euthanasia: a qualitative study investigating the experience of general practitioners. *J Med Ethics* 2008; 34(3): 150–155.
14. De Scheur G, Van der Arend A, Spreeuwenberg C, et al. Euthanasia and physician-assisted suicide in the Dutch home-care sector: the role of the district nurse. *J Adv Nurs* 2007; 58(1): 44–52.
15. De Scheur G, Van der Arend A, bu-Saad H, et al. The role of nurses in euthanasia and physician-assisted suicide in The Netherlands. *J Med Ethics* 2008; 34(4): 254–258.
16. Jansen-Van der Weide M, Onwuteaka-Philipsen B and Van der Wal G. Requests for euthanasia and physician-assisted suicide and the availability and application of palliative options. *Palliat Support Care* 2006; 4(4): 399–406.
17. Elwyn G, Frosch D, Thomson R, et al. Shared decision-making: a model for clinical practice. *J Gen Intern Med*. 2012; 27:1361-1367.
18. O'Riordan M, Dahinden A, Aktürk Z, et al. Dealing with uncertainty in general practice: an essential skill for the general practitioner. *Qual Prim Care* 2011; 19(3): 175–181.
19. Entwistle V, Caerter S, Cribb A, et al. Supporting patient autonomy: the importance of clinician-patient relationships. *J Gen Intern Med* 2010; 25(7): 741–745.
20. Légaré F, Ratté S, Gravel K, et al. Barriers and facilitators to implementing shared decision-making in clinical practice: update of a systematic review of health professionals' perceptions. *Patient Educ Couns* 2008; 73(4): 526–535.
21. Elwyn G, Edwards A and Kinnersley P. Shared decision-making in primary care: the neglected second half of the consultation. *Br J Gen Pract* 1999; 49(443): 477–482.
22. Charles C, Gafni A and Whelan T. Shared decision-making in the medical encounter: what does it mean? (Or it takes at least two to tango.) *Soc Sci Med* 1997; 44(5): 681–692.
23. Elwyn G, Laitner S, Coulter A, et al. Implementing shared decision making in the NHS. *BMJ* 2010; 341: c5146.
24. Schön D (ed.). *The reflective practitioner: how professionals think in action*. London: Temple Smith, 1983.
25. Staatscommissie Euthanasie. *Rapport inzake euthanasie* [Report concerning euthanasia, in Dutch.]. Den Haag: Staatsdrukkerij en uitgeverij, 1985.
26. Britten N. Qualitative interviews in medical research. *BMJ* 1995; 311(6999): 251–253.
27. Pasman H, Rurup M, Willems D, et al. Concept of unbearable suffering context of ungranted requests for euthanasia: qualitative interviews with patients and physicians. *BMJ* 2009; 339: b4362.

28. Kendall M, Murray S, Carduff E, et al. Use of multiperspective qualitative interviews to understand patients' and carers' beliefs, experiences, and needs. *BMJ* 2009; 339: b4122.
29. Murray S, Kendall M, Carduff E, et al. Use of serial qualitative interviews to understand patients' evolving experiences and needs. *BMJ* 2009; 339: b3702.
30. Pope C and Mays N. Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *BMJ* 1995; 311(6996): 42–45.
31. Spencer L, Ritchie J and O'Connor W. Analysis: practices, principles, processes. In: Ritchie J and Lewis J (eds) *Qualitative research practice: a guide for social science students and researchers*. London: SAGE, 2007.
32. Kondracki N, Wellman N and Amundson D. Content analysis: review of methods and their applications in nutrition education. *J Nutr Educ Behav* 2007; 34: 224–230.
33. Mayring P. Qualitative content analysis. Forum qualitative sozialforschung/forum: qualitative social research, ed. 1 June 2000. <http://www.qualitative-research.net/index.php/fqs/article/viewArticle/1089/2385> (accessed September 2012).
34. Rurup M, Onwuteaka-Philipsen B, Jansen-Van der Weide M, et al. When being 'tired of living' plays an important role in a request for euthanasia or physician-assisted suicide: patient characteristics and the physician's decision. *Health Policy* 2005; 74: 157–166.
35. Levene I and Parker M. Prevalence of depression in granted and refused requests for euthanasia and assisted suicide: a systematic review. *J Med Ethics* 2011; 37: 205–211.
36. Kimsma G. Death by request in the Netherlands: facts, the legal context and effects on physicians, patients and families. *Med Health Care Philos* 2010; 13: 355–361.
37. Van Marwijk H, Haverkate I, Van Royen P, et al. Impact of euthanasia on primary care physicians in the Netherlands. *Palliat Med* 2007; 21: 609–414.
38. Rapley T. Distributed decision making: the anatomy of decisions-in-action. *Sociol Health Illn* 2008; 30: 429–444.
39. Norwood F, Kimsma G and Battin M. Vulnerability and the 'slippery slope' at the end-of-life: a qualitative study of euthanasia, general practice and home death in the Netherlands. *Fam Pract* 2009; 26: 472–840.
40. Belanger E, Rodriguez C and Groleau D. Shared decision-making in palliative care: a systematic mixed studies review using narrative synthesis. *Palliat Med* 2011; 25: 242–261.
41. Back AL, Starks H, Hsu C, et al. Clinician-patient interactions about requests for physician-assisted suicide: a patient and family view. *Arch Intern Med* 2002; 162: 1257–1265.
42. Swarte N, Van der Lee M, Van der Bom J, et al. Effects of euthanasia on the bereaved family and friends: a cross sectional study. *BMJ* 2003; 327(7408): 189–194.