

University of Groningen

Considerations on requests for euthanasia or assisted suicide; a qualitative study with Dutch general practitioners

ten Cate, Katja; van Tol, Donald G.; van de Vathorst, Suzanne

Published in:
Family practice

DOI:
[10.1093/fampra/cmz041](https://doi.org/10.1093/fampra/cmz041)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2017

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

ten Cate, K., van Tol, D. G., & van de Vathorst, S. (2017). Considerations on requests for euthanasia or assisted suicide; a qualitative study with Dutch general practitioners. *Family practice*, 34(6), 723-729. <https://doi.org/10.1093/fampra/cmz041>

Copyright

Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license. More information can be found on the University of Groningen website: <https://www.rug.nl/library/open-access/self-archiving-pure/taverne-amendment>.

Take-down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Downloaded from the University of Groningen/UMCG research database (Pure): <http://www.rug.nl/research/portal>. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.

Qualitative Research

Considerations on requests for euthanasia or assisted suicide; a qualitative study with Dutch general practitioners

Katja ten Cate^{a,*}, Donald G van Tol^b and Suzanne van de Vathorst^{a,c}

^aDepartment of General Practice, section Medical Ethics, Academic Medical Center, Amsterdam, The Netherlands,

^bDepartment of General Practice, University Medical Center Groningen, Groningen, The Netherlands and ^cDepartment of Medical Ethics and Philosophy, Erasmus Medical Center, Rotterdam, The Netherlands.

*Correspondence to Katja ten Cate, Department of General Practice, Section Medical Ethics, Room J2-219, Academic Medical Center, P.o. box 22660, 1100 DD Amsterdam, The Netherlands; E-mail: k.tencate@amc.uva.nl

Abstract

Background. In the Netherlands, euthanasia or assisted suicide (EAS) is neither a right of the patient nor a duty of the physician. Beside the legal requirements, physicians can weigh their own considerations when they decide on a request for EAS.

Objective. We aim at a better understanding of the considerations that play a role when physicians decide on a request for EAS.

Methods. This was a qualitative study. We analysed 33 interviews held with general practitioners (GPs) from various regions in the Netherlands.

Results. The considerations found can be divided in three main types. (i) Perceived legal criteria, (ii) individual interpretations of the legal criteria and (iii) considerations unrelated to the legal criteria. Considerations of this 3rd type have not been mentioned so far in the literature and the debate on EAS. Examples are: the family should agree to EAS, the patient's attitude must reflect resignation, or conflicts must be resolved.

Conclusions. Our study feeds the ethical discussion on the tension that can arise between a physician's own views on death and dying, and the views and preferences of his patients. When considerations like 'no unresolved conflicts' or 'enough resignation' influence the decision to grant a request for EAS this poses questions from an ethical and professional point of view. We hypothesise that these considerations reflect GPs' views on what 'good dying' entails and we advocate further research on this topic.

Key words: Assisted suicide, euthanasia, legislation as topic, medical ethics, palliative care, primary health care.

Introduction

In the Netherlands, euthanasia or assisted suicide (EAS) largely takes place within general practice; in 2014, 88% of the EAS cases were performed by a GP (1). Patients who have a wish to die can request their treating physician, mostly a GP, to perform either euthanasia (in which the physician administers a lethal dose of a suitable drug to a patient) or assisted suicide (where the physician supplies the drug but the patient administers it himself). The same regulations apply to both options (2). When Dutch physicians perform EAS,

they need to comply with the legal criteria of due care, laid down in the Termination of Life on Request and Assisted Suicide (Review procedures) Act (2). These legal criteria of due care are listed in text box below.

EAS is neither a right of the patient nor a duty of the physician; physicians can weigh their own considerations when deciding on an EAS request. In this study, we aim at a better understanding of those considerations playing a role for physicians deciding on an EAS request.

1. The physician must be satisfied that the patient has made a voluntary and carefully considered request;
2. The physician must be satisfied that the patient's suffering is unbearable, and that there is no prospect of improvement;
3. The physician must have informed the patient about his situation and his prospects;
4. The physician must have come to the conclusion, together with the patient, that there is no reasonable alternative in the light of the patient's situation;
5. The physician must have consulted at least one other, independent physician, who must have seen the patient and given a written opinion on the due care criteria referred to above;
6. And the physician must terminate the patient's life or provide assistance with suicide with due medical care and attention.

The Act is designed to shield physicians against criminal liability, not to empower patients. Compassion of the physician with his suffering patient is the key rationale of the Act, not the autonomy of the patient; although a voluntary and careful considered request is a necessary prerequisite, it is not a sufficient one (3,4).

The due care criteria are adopted from Dutch case law on EAS (in particular, the Postma case (1973) and the Schoonheim case (1984)) (3,4). The Chabot case (1994) and the Brongersma case (2002) are two other influential cases from Dutch case law. In both these cases, the criterion of unbearable suffering, that was already developed in earlier cases, was refined (3,4). In 1994, the Supreme Court ruled in the Chabot case that it is the severity of the suffering (in combination with the lack of prospect of improvement) that counts, not the cause of the suffering (5). This vision of the Supreme Court found support in the parliamentary debates on the Act before it came into force in 2002 and is one of the foremost reasons the Act does not discriminate between physical and psychiatric suffering (5). This does not mean though, that any perceived suffering is allowed to be a ground for a physician to perform EAS. In 2002, the Supreme Court ruled in the Brongersma case that the suffering of the patient needs to originate mainly in a medically classified condition for a physician to escape criminal liability when he performs EAS. Suffering caused by other than medical conditions was thought to lie outside the domain of medical expertise (6). This is still the current judicial norm.

The Dutch legislator has purposefully formulated the due care criteria in an open and abstract manner (3,4). According to Griffiths and Pans, the legislator has done so with the intention to do justice to the specificity of individual cases and to allow for the interpretation of the criteria to shift in accordance with changes in public and professional opinion (3,4). The Regional Review Committees have recently published a 'Code of practice' in which physicians are given guidance on how the due care criteria can be interpreted in practice (7). Nevertheless, the open and abstract formulation of the criteria implies that physicians are to apply and interpret the criteria themselves when they receive a concrete request for EAS. Furthermore, there is, in Dutch practice, room for physicians' own considerations that may not be related to the legal criteria or the interpretation of those criteria. Because EAS is thought of as an extraordinary action, not belonging to normal medical practice, physicians are, at least where the Dutch Act on EAS is concerned, free to make their own considerations and to refuse a request at any time and for whatever reason (3,4).

To get a better picture of the considerations that play a role when physicians decide on a request for EAS, we analysed 33 in-depth interviews held with general practitioners (GPs) from various regions in the Netherlands. Since EAS in the Netherlands largely takes place

within general practice, this is the place to look for physicians' considerations regarding EAS requests.

We had the following research question: what considerations play a role in practice when Dutch GPs have to decide on an EAS request?

Methods

The 33 qualitative interviews with Dutch GPs, that we report on here, were conducted earlier (in 2010) as part of a large nationwide study into the knowledge and opinions of the general public and professionals on decision-making and treatment at the end of life: The KOPPEL study (8,9).

We used two different sets of interviews from the KOPPEL study; one set of 18 interviews with Dutch GPs about their experiences, knowledge and opinions regarding EAS, and another set of 15 interviews with Dutch GPs that were more specifically about reasons for granting an EAS request or not. Although the two sets of interviews had a different aim and topic-list, both sets of interviews proved to be a rich source of considerations that play a role in deciding on EAS. That is the reason we combined both sets of interviews, and did a secondary analysis on them with our own research question.

Data collection (KOPPEL study)

The first set of interviews (18) was about GPs' experiences, knowledge and opinions regarding EAS. For this set of interviews, the KOPPEL researchers made a list of 25 GPs who had been taking part in the quantitative survey of the KOPPEL study and had indicated that they were willing to take part in a follow-up interview study. This list of 25 potential interviewees came about through purposive case selection. Two factors played an important role in this selection: experience with and attitude towards EAS. Attitude towards EAS was categorized as liberal, neutral or conservative, based on respondents' answers to five statements about autonomy and EAS from the KOPPEL's quantitative survey. The statements had a five point likert scale from totally agree to totally disagree and were:

- 'I believe everyone has the right to get EAS if so desired'.
- 'I believe EAS should be allowed for people who have a wish to die but do not suffer from a severe disease'.
- 'I believe everyone has the right to decide about his own life and death'.
- 'I believe a physician should stop medical treatment if the patient requests that'.
- 'I believe elderly people who wish to die should get lethal drugs to end their own lives if they wish'.

On the basis of the answers to these five statements, an additive 'right to die'-index was built by the KOPPEL researchers. The items used to build the index show a high internal consistency (Cronbach alpha: 0.81). The minimum score on this index was 5, the maximum was 25. A score between 5 and 14 was categorized as conservative, a score of 15–19 as neutral and a score of more than 19 was categorized as liberal. Age and gender were no selection criterion in the purposive case selection but these characteristics were post hoc checked for to make sure distribution was balanced.

From this list of 25 selected cases, 18 were eventually interviewed, because at that point data saturation was reached. Every time a next respondent from the list was invited to give an interview, the KOPPEL interviewers tried to keep the distribution balanced. Eventually, eight GPs with a liberal attitude, eight with a conservative

and two with a neutral attitude were interviewed. Fifteen GPs with experience with EAS were interviewed and three without. Twelve respondents were male, six were female. Respondents' age ranged from 35 to 61 years, with a mean age of 49.4 years. Table 1 shows the characteristics of these 18 respondents.

Three separate interviewers (BV, PK and DT) conducted these 18 interviews. The interviews were conducted at the GPs' working place and lasted about an hour. Before the start of the interview, the voluntary character and confidentiality of participation were emphasised. Respondents agreed to the interviews being recorded with an audio recording device. The interviews were semi-structured with the use of an interview guideline with open questions and topics. First, the respondents were asked about their thoughts regarding euthanasia. To explore opinions about EAS further, participants were asked what they would tell a foreign colleague about Dutch EAS practice and how it is regulated. The GPs were asked to reflect on vignettes that were also used in the quantitative questionnaires. Finally, personal experiences (if any) with (requests for) EAS were discussed. The interview guideline was tested in a pilot study for length and comprehensibility by all three interviewers. This led to some minor adjustments. Because several researchers performed the interviews, the use of the interview guideline was discussed and practised intensively during an interview-training weekend set up for this purpose. One of the interviewers (BV) monitored the degree of saturation by reading all the interviews to see whether any new opinions, thoughts and patterns of reasoning were brought up.

The second set of interviews (15) with other GPs was more specifically about reasons for granting an EAS request or not. These respondents were selected via snowball sampling; after an interview respondents were asked if they would know of other eligible interview candidates, preferably people they thought would have a different opinion on EAS. After 15 interviews, no more new considerations came up; data saturation was reached. Gender and age were distributed as follows: nine respondents were male, six were female, age ranged from 37 to 63 years, with a mean age of 51.2 years. Three

GPs worked in a large city, six in a smaller city, one in a large village and five in a rural area. All had experience with rejecting EAS requests. Table 2 shows the characteristics of these 15 respondents. These interviews were all done by SV. First, respondents were asked about the most recent case in which a patient requested them to perform EAS but they refused the request. They were also asked about the case they remembered best. By 'a refused request' situations were meant where the patient requested EAS but the GP refused the request or postponed the decision until it was too late to perform EAS. The reasons for refusing the request were further explored, with the following aspects in mind: knowledge on the legal regulations, interpretation of the situation, prior experiences with EAS (positive or negative), behaviour and attitude of family and patient, and the respondent's opinions regarding EAS.

As Tables 1 and 2 show, a heterogeneous group of GPs is interviewed. The purposive sampling of the first set of interviews, as well as the snowball sampling in the way it was done in the second set of interviews, contribute to finding a wide range of different opinions, thereby increasing the validity of the study (10).

Data analysis

For our analysis, we combined both set of interviews, so we reanalysed 33 interviews in total. This analysis was done by KC and SV, with help of MaxQDA, software for the analysis of qualitative data. All interviews were read several times. Fragments in which respondents talked about their considerations for granting or refusing a request for EAS were given one or more codes (open coding). KC and SV compared and discussed the differences and similarities in their coding, which led to a refinement of the code tree. The coded fragments were further analysed by KC during several phases of coding (axial and selective coding); codes were refined, sub codes and overarching codes were assigned and relationships between codes were explored. Interviews were also analysed as a whole, to look for patterns and inconsistencies in reasoning.

Results

By analysing the interviews, we found that quite a number of different considerations come into play when Dutch GPs have to decide upon a request for EAS. We have divided these considerations in three main types: (i) perceived legal criteria, (ii) individual interpretation of the legal criteria and (iii) considerations unrelated to the legal criteria.

Perceived legal criteria

Respondents obviously take into account the legal criteria (see text box) when they have to decide on a request for EAS. However, in the interviews we found that several respondents perceive some things to be legally required while these are not.

This respondent, for example, answers that he thinks a life expectancy of less than 2 weeks is legally required when he is asked in which case EAS would be allowed.

R: 'The disease must lead to death within the foreseeable future, right? But I thought there was also case law saying that this life expectancy of two weeks mentioned in the law can be longer, but I'm not totally sure about that.' (R10)

Another respondent answers he thinks unbearable pain is a legal requirement, in reaction to questions about a vignette of a cancer patient whose suffering is mainly psychological and existential in nature.

Table 1. Characteristics of respondents interview set 1 (18 Dutch GPs interviewed in 2010)

Gender	Age	Attitude on EAS according to 'right to die index' KOPPEL survey	Number of EAS performed
M	44	Liberal	1-2
M	61	Liberal	1-2
M	54	Liberal	>2
M	58	Liberal	>2
M	47	Liberal	>2
F	51	Liberal	>2
F	44	Liberal	>2
M	52	Liberal	>2
F	35	Conservative	none
F	56	Conservative	none
M	51	Conservative	none
M	58	Conservative	1-2
F	38	Conservative	1-2
M	45	conservative	1-2
M	52	conservative	>2
F	45	conservative	>2
M	unknown	neutral	1-2
M	unknown	neutral	1-2

M, male; F, female.

Table 2. Characteristics of respondents interview set 2 (15 Dutch GPs interviewed in 2010)

Gender	Age	Years of experience as GP	Geographical area	Specific population
M	47	15	Rural area	No specific features
F	49	18	City	Many young people
M	56	26	City	Many elderly
M	53	23	City	No specific features
M	43	11	City	No specific features
F	57	11	Rural area	No specific features
F	63	35	Large city	Many young people, immigrants and drug addicts
M	52	20	Rural area	Many people with high level of education
F	56	20	City	No specific features
M	57	28	City	No specific features
M	49	15	Large village	Many elderly
M	37	6	Rural area	Many elderly
M	38	6	Rural area	Many elderly and people with low education and SES
F	55	23	Large city	Many young people, many people with psychiatric problems
F	56	22	Large city	No specific features

M, male; F, female.

R: 'She doesn't have physical complaints, like pain. I think unbearable pain is a condition to legally perform euthanasia.' (R14)

In reaction to the same vignette of the cancer patient whose suffering is mainly psychological and existential, the following respondent combines the two misunderstandings and says he thinks physical suffering as well as a disease in a terminal stage are legally required.

R: 'No, this is not legally allowed, because this physician is not cornered. It is only allowed when one is on the horns of a dilemma; I mean when the suffering is so severe there is no other solution.'

I: 'and if this same woman would also get physical complaints that cannot be controlled adequately with medication?'

R: 'Then it would be allowed, but only if she would be in a terminal stage of disease.' (R16)

Another common misunderstanding is the need for a written request; this is not legally required while several respondents think it is.

Individual interpretations of the legal criteria

When GPs receive a concrete request for EAS, they have to apply the law's rather abstract and openly formulated criteria to a real life case. Respondents differed in how they apply the legal criteria. For example, they differed in what they understand and recognise as 'unbearable suffering with no prospect of improvement'. This type of considerations does not stem from incorrect knowledge of the legal criteria like the type of considerations described above, but rather from respondents' individual interpretation of these legal criteria.

This respondent for example says he would find it very hard to perform EAS with a patient who can still walk, talk and eat; apparently the suffering of a patient in such a situation would not (yet) classify as unbearable in this GP's view.

R: 'Some patients who have been told they can't be cured anymore say after a couple of weeks: 'I feel I'm getting more tired, my condition declines, this last phase of life, I just don't want it'. It would be very hard for me to perform EAS in such situations, when the patient can still move around in his home. Performing EAS on a patient who is still able to talk, to eat, no, it would be a bridge too far in my opinion. (...) Look, if someone isn't able to eat anymore, to drink anymore, feels terrible, is nauseated, vomits a lot of the time, is extremely weakened or has a lot of pain, okay. But without that, I think of someone

still walking around. No I won't do that [perform EAS], that would be too hard for me.' (R14)

Many other respondents also mention that psychiatric, psychological and/or existential suffering alone would make it very hard for them to empathise with a patients' unbearable suffering.

R: 'This request was from a woman with oesophagus cancer, with liver metastasis. So of course, her condition declined slowly, but so far there were no real physical complaints. But she lived alone and didn't accept any help, like home care. She had always been very independent and active. And actually, she wanted to die before she became dependent. Here, we differed of opinion. She suffered from loss of autonomy and a fear of dependency. And she thought her life was meaningless. But I couldn't empathise with that; I thought her condition was still too good to perform EAS.' (R13)

Others state it a bit differently and speak of their feeling they could only perform EAS on patients who have a life-threatening disease, or who are in the final stage of life. For example, this respondent who explains that in his view EAS might only be a solution for people in the last weeks of their lives.

R: 'A colleague of mine, who works in the same building, recently got an EAS request from a patient with MS. This patient might have lived for another year or two, but didn't want to experience that process of decline. My colleague granted the request. For me that would be very hard. I don't think I would have done that. As a doctor, I don't want to help such patients to step out of life early. My view on EAS is that it is only a solution in the terminal stage, the very last weeks.' (R2)

Another respondent seems to have just the opposite viewpoint. For him, EAS might be a solution for those patients whose suffering will not be ended by a natural death in the near future.

R: 'I tell patients who want EAS that they need to have a life expectancy of more than two weeks, otherwise I'm not even considering it. Otherwise we will just wait for death to come naturally and use palliative sedation if necessary. (...) For me, EAS is really for those cases where the suffering will last so long, and where death will not save the patient at short notice, because in those cases there are no other solutions and you have to act.' (R30)

Respondents also differ in their interpretation of the ‘voluntary and carefully considered request’ criterion. Many mention, for example, that they want their patients to write their requests down. Only then they are satisfied that the patient has carefully considered his request. The following respondent mentions a patient with a request for EAS, whom he visited very frequently during several weeks because he wanted to be sure her request was consistent. For this physician ‘carefully considered’ means ‘repeatedly done over a longer period of time’.

R: ‘A case in which I had a lot of doubts whether to grant the request was a case of a paraplegic woman in her early fifties with two amputated legs. Her condition rapidly declined, she was malnourished and had very severe pressure ulcers. She had spent a year in a rehab clinic just to attain some improvement on those pressure ulcers, but that didn’t help. Her plastic surgeon told her there was nothing else that could be done to improve her wounds and that, at a certain moment, these wounds would cause multiple organ failure and she would die. At that point she asked me to perform EAS. I found that very difficult, because she didn’t have a fatal disease like cancer – although she had a very poor prognosis, of course. I took a lot of time to talk to her, because her request was not consistent to me, or at least: she had never spoken to me before about EAS. I wanted to be sure her request was consistent. First I tried to have her admitted to a nursing home or a hospice, with the idea that if she was pampered her request might disappear. But everything was full so we arranged a lot of home care. But she stayed in severe pain because of those wounds. I visited her very frequently during some weeks. Sometimes I saw her every day, just to talk to her about her request. But every time she ensured me her wish wasn’t going to change. So eventually, I felt I had no other option than to help her die.’ (R20)

Another respondent wants to have deep conversations on life and death with a patient before he can be satisfied a request is carefully considered.

R: ‘It is not totally up to me and what I think about it or just about the type of disease, it also has to do with what kind of person is asking me. If I think about EAS, this implies, for me, a lot of talk, talk about death and dying, talk about life, about saying goodbye, really seeing and feeling what is happening in this last phase of life and reflect on that. But not everybody is capable of talking and reflecting this way, while everybody is going to die. So that’s my problem. For me talking about and reflecting on life and death is a necessary condition to perform EAS. But you can’t reasonably expect that from certain people, that they are able to do that. Perhaps I should recognise that earlier and say to those people: sorry I won’t be able to perform EAS on you because I can’t have a deep enough conversation with you about it and then it doesn’t feel right. And I learned not to do these things when it doesn’t feel 100% right, otherwise I can’t sleep at night. But the thing is, I do treat people unequally this way.’ (R33)

Considerations unrelated to the legal criteria

Apart from the legal criteria that were sometimes incorrectly understood and differently applied by our respondents, we also found that considerations play a role that have little or nothing to do with the legal criteria.

The Dutch Act on EAS, for example, does not require a (treatment) relationship between physician and patient, but many respondents mention that for them it is important to have a good relationship with the patient in order to be able to perform EAS.

This respondent, for example, says he wants to know a patient well before the patient becomes ill.

R: ‘I once got a request for EAS from a terminally ill patient while I was standing in for a colleague who was on a holiday for a couple of weeks. I said to this patient: ‘Listen, I work here temporarily, I am prepared to do a lot for you, but one thing must be absolutely clear: I won’t perform EAS on you.’ That is a line I won’t cross, because I hardly knew him. (...) I believe you should know a patient and his family well if you want to perform EAS. You should have a close relationship. That doesn’t mean you have to go back for years, but I do believe you should know somebody before he became ill, so you know how he is, how he thinks about life et cetera and that you had the opportunity to monitor the course of illness.’ (R19)

The Dutch Act also does not mention the role of family members. In practice, however, for many respondents family members play an important role in the decision making process. This is the case, for example, for the following two respondents who seem to believe that it is important for a ‘good death’ that there are no unresolved conflicts in the family.

R: ‘If the family doesn’t agree with the EAS there are probably some unresolved issues in the family, you get the feeling some things aren’t completed yet. And in case of real family conflicts, performing EAS would be very hard for me. I think I would not do it then, no. And I think I would discuss this with the patient too: “don’t you agree that this is a very harsh time to perform EAS while there are conflicts in your family? Shouldn’t those be resolved first?”’ (R4)

R: ‘I always ask patients, in private, if there are things from the past that haven’t found closure yet, conflicts and that kind of things. I think that is important when I help someone die, that there are no unresolved issues or unfinished business.’ (R8)

Also other respondents mention that it is important for them that family members agree with the EAS.

R: ‘Family is essential. I would never perform EAS if the family does not agree, that is asking for trouble.’ (R18)

Some respondents seem to be reluctant to perform EAS when their patients’ attitude to life differs from their own. This respondent, for example, expects his patients to fight for their life and not give up ‘too easily’.

R: ‘This case concerned a man with lung cancer who didn’t want palliative chemotherapy anymore. But I managed to convince him to take palliative chemo for a second and even a third time..well, he did die during that last chemo. But the thing was, he had been very sick from the first palliative chemo and didn’t want to experience that another time, so he came to me for EAS. And I had a lot of problems with that. I also told him this, that I couldn’t perform EAS on him. Because it clashed so fundamentally with my view: fighting for your life, doing everything possible. Okay, he couldn’t be cured anymore, but his situation wasn’t unbearable yet, he just didn’t want to go on anymore. His attitude, that was my problem with it.’ (R23)

Another respondent says it is important for him that patients have found acceptance and be at peace with their situation, in order for him to be able to perform EAS.

R: ‘He told me he wanted to walk normally, to function normally, he didn’t want home care; he just didn’t want Parkinson’s disease, that was it. And perhaps, just looking at the law, you could write up his story in such a way that the review committees would condone it. But it felt so wrong. This man, he was just so

defiant and sad that he lost his mobility. I thought let's see if he is able to accept his situation and then we can talk from there. (...) Such an opposing attitude, I see that more often from people requesting EAS. And it gives me the feeling it is not the right time yet, that EAS would come too early. [It is the right time for EAS] Only if someone is totally at peace with himself, his life and his death, and if I see and feel that too.' (R27)

Conclusions

For Dutch GPs, different considerations play a role when they have to decide upon a request for EAS. These considerations can be divided in three main types: (i) perceived legal criteria, (ii) individual interpretations of the legal criteria and (iii) considerations that are unrelated to the legal criteria.

GPs obviously consider the legal criteria, but are not always correct in what they think these legal criteria are. For example, a life threatening disease, severe physical suffering, a disease in a terminal stage or a written request are incorrectly thought of as legally required.

But even if GPs are correct about the legal criteria, they have to interpret these criteria to apply them to concrete cases. In practice, we see quite a bit of variation in this interpretation. GPs differ mainly in what they would classify as unbearable suffering. The stage of the disease the patient has reached, his degree of decline or the nature of his suffering are factors that influence GPs assessment of the patient's unbearable suffering. This variation in the interpretation and application of the unbearable suffering criterion is also described in earlier research. Quantitative studies on the Dutch EAS practice show that while most physicians will classify severe physical suffering as pain, vomiting, fatigue and dyspnoea in a patient in a terminal stage of disease as unbearable, suffering in an earlier stage of the disease or suffering which is more psychological or existential in nature is less often recognized as unbearable and is a reason to reject a request for EAS (11–14). Pasma *et al.* conducted qualitative research with Dutch GPs and relatives of patients about EAS and concluded too that there was often no agreement between physicians and patients about what constitutes unbearable suffering; patients put more emphasis on psychosocial suffering, such as dependence and deterioration, whereas physicians referred more often to physical suffering. In some cases, the physician thought that the suffering was not unbearable because the patient's behaviour seemed incompatible with unbearable suffering—for instance, because the patient was still reading books (15). Van Tol *et al.* also found a lot of variation in the application of the unbearable suffering criterion in their qualitative research with Dutch GPs (16). They offer two explanations for this variation. They show that GPs follow different cognitive routes when assessing a patients' suffering in the context of an EAS request; by imagining how it would be to experience the situation of the patient himself ('imagine self') or by imagining what the situation must be like for this particular patient ('imagine other'). But they also show that most GPs associate the classification of suffering as 'unbearable' directly with granting the patient's request and thus with actually performing EAS. They write: 'this brings in personal values and believes about euthanasia in general and the actual act of terminating this individual's life in particular. It means that the process of assessing a patient's suffering and the decision to grant a request or not, will often be influenced by a doctors personal normative beliefs about euthanasia; the kind of suffering she thinks may justify it' (16). In a quantitative survey on the application of the unbearable suffering criterion, Van Tol *et al.* found no relation with physicians' gender, age or training on the one hand, and the judgment of patients' suffering as unbearable

or the willingness to grant the request on the other hand (in hypothetical vignettes). They did find a relationship with experience with EAS; physicians who performed EAS at least once during the past 5 years more often considered the patient's suffering as unbearable and were more often willing to grant the request (17).

What our study adds to this knowledge is that it is not only a GP's personal interpretation of the legal criteria (notably the unbearable suffering criterion) that influences the decision on an EAS request; we found that GPs also have considerations that have nothing to do with the legal requirements (type 3). Examples are: the family must agree, unresolved family issues need to be addressed first, or the patient's attitude must reflect resignation.

Considerations of this 3rd type have not been mentioned this explicitly in the literature on EAS so far, probably because physicians are not very aware they have these considerations. Such considerations might only come to the surface when physicians are asked to explain thoroughly why they struggled with particular requests for EAS, as was done in the in-depth interviews of our study.

We hypothesise that these type of considerations stem from GPs' underlying views on what 'good dying' entails. For GPs in whose opinion 'good dying' entails that there are no unresolved issues and that the patient dies harmoniously and with resignation, (family) conflicts or a patient still angry and combative might form a problem for granting the EAS request.

When physician's considerations stay implicit and are not openly discussed between physician and patient this can lead to miscommunication and diverging mutual expectations. That may harm the quality of the last phase of the patient's life, as well as the bereavement process of relatives. To minimise such situations we would like to encourage physicians to reflect on their own interpretation of the legal criteria and additional aspects they may value beside the legal criteria, and to discuss their considerations openly and timely with their patients. This will also enable patients to search for another physician if so desired.

We also think that it is important that in GPs' training more attention is paid to the (correct) legal criteria; it should be avoided that a request for EAS gets refused because a physician mistakenly thinks EAS would not be legally allowed in a certain case while he would be willing to perform it otherwise.

Apart from pointing to these practical recommendations our study can also feed the ethical discussion on the tension that can arise between a physician's own views on death and dying, and the views and preferences of his patients. Next to the abovementioned miscommunication and diverging mutual expectations owing to considerations that remain implicit, there are other aspects to physicians' considerations that can be problematic for patients and could raise ethical concerns. For example, to find peace and acceptance with the situation, to restore contact with family members or to solve conflicts, can be extra burdensome for patients who are already in a situation they experience as unbearable. Moreover, one could question whether GPs impose their views on what 'good dying' looks like on their patients when considerations like 'no unresolved conflicts' or 'enough resignation' influence the decision to grant a request or not, and whether this is problematic from a moral and professional viewpoint.

These interviews were not conducted with our exact research question in mind. Although the data revealed many examples of the considerations that play a role in practice, the interviews were not specifically about unravelling the views behind them. Especially our new finding that in practice considerations play a role that have little to do with the legal requirements but, as we hypothesise, reflect GPs' views on what 'good dying' entails (type 3), should be studied more in-depth in future research. Furthermore, since this was a qualitative study it is not possible to link characteristics of the respondents such

as gender, age, training or experience to our findings. It would be interesting to conduct quantitative research too to see whether there might be a relationship between such characteristics and the degree in which GPs let their own ideas on death and (assisted) dying influence their decisions on an EAS request.

The findings of this future research into GPs' views on death and dying are not only relevant for the Dutch EAS debate, but can also be informative for (research into) other end-of-life practices, in the Netherlands as well as abroad, because having a 'good death' and having a caregiver that can attribute to that is of importance to everyone, not only for those requesting EAS.

Acknowledgements

We like to thank all the GPs who provided the data for this manuscript; we especially appreciate the openness with which they shared their experiences on this sensitive topic. We also like to thank the interviewers from the KOPPEL-study for collecting the data (Bea van der Vegt and Pauline Kouwenhoven), and other members of the KOPPEL-study's research team for being so generous to share some of this data with us for a secondary analysis. We thank the members of the advisory committee of KC's project and the members of the section Medical Ethics from the Academic Medical Center for commenting on a draft of this article. We would also like to thank ZonMw and the NVVE for their financial support.

Declaration

Funding: the interviews this manuscript reports on were held in the context of the KOPPEL-study, which was funded by ZonMw, The Netherlands Organisation for Health Research and Development. KC reanalysed the interviews in the context of her PhD project at the Academic Medical Center, a project that is funded by the NVVE, the Right to Die Society in the Netherlands. ZonMw and the NVVE had no role whatsoever in the design, the collection, analysis and interpretation of the data, the reporting of this work, or the decision to submit the work for publication.

Ethical approval: according to Dutch regulations no ethical approval was required for this study.

Conflict of interest: none.

References

1. Regional Euthanasia Review Committees. *Annual report 2014*. The Hague, The Netherlands 2015.
2. Dutch Ministry of Justice. [Termination of Life on Request and Assisted Suicide (Review procedures) Act]. *Staatsblad*. 2001; 194: 1–8.
3. Griffiths J, Bood A, Weijers H. *Euthanasia and Law in the Netherlands*. Amsterdam, The Netherlands: Amsterdam University Press, 1998.
4. Pans E. *De Normatieve grondslagen van het Nederlandse Euthanasierecht [The normative grounds of the Dutch Euthanasia law]*. Nijmegen, The Netherlands: Wolf Legal Publishers, 2006.
5. HR 21 June 1994. *Nederlands Juristenblad*. 1994(656).
6. HR 24 December 2002. *Nederlands Juristenblad*. 2002(167).
7. Regional Euthanasia Review Committees. *Code of practice*. The Hague, The Netherlands, 2015.
8. van Delden JJM, van der Heide A, van de Vathorst S, Weyers H, van Tol DG. *[Knowledge and opinions of the general public and professionals on medical decision making and treatment in the end of life; the Koppel-research]*. The Hague: ZonMw [The Netherlands Organisation for Health Research and Development], 2011.
9. Kouwenhoven PS, Raijmakers NJ, van Delden JJ *et al*. Opinions of health care professionals and the public after eight years of euthanasia legislation in the Netherlands: a mixed methods approach. *Palliat Med* 2013; 27: 273–80.
10. Strauss AL, Corbin J. *Basics of qualitative research: techniques and procedures for developing grounded theory*. Thousand Oaks, CA: Sage; 1998.
11. Onwuteaka-Philipsen BD, Rurup ML, Pasman HR, van der Heide A. The last phase of life: who requests and who receives euthanasia or physician-assisted suicide? *Med Care* 2010; 48: 596–603.
12. Bolt EE, Snijdewind MC, Willems DL, van der Heide A, Onwuteaka-Philipsen BD. Can physicians conceive of performing euthanasia in case of psychiatric disease, dementia or being tired of living? *J Med Ethics* 2015; 41: 592–8.
13. Jansen-van der Weide MC, Onwuteaka-Philipsen BD, van der Wal G. Granted, undecided, withdrawn, and refused requests for euthanasia and physician-assisted suicide. *Arch Intern Med* 2005; 165: 1698–704.
14. Rietjens JA, van Tol DG, Schermer M, van der Heide A. Judgement of suffering in the case of a euthanasia request in The Netherlands. *J Med Ethics* 2009; 35: 502–7.
15. Pasman HR, Rurup ML, Willems DL, Onwuteaka-Philipsen BD. Concept of unbearable suffering in context of ungranted requests for euthanasia: qualitative interviews with patients and physicians. *BMJ* 2009; 339: b4362.
16. van Tol DG, Rietjens JA, van der Heide A. Empathy and the application of the 'unbearable suffering' criterion in Dutch euthanasia practice. *Health Policy* 2012; 105: 296–302.
17. van Tol D, Rietjens J, van der Heide A. Judgment of unbearable suffering and willingness to grant a euthanasia request by Dutch general practitioners. *Health Policy* 2010; 97: 166–72.