PALLIATIVE MEDICINE

Original Article

Similarities and differences between continuous sedation until death and euthanasia – professional caregivers' attitudes and experiences: A focus group study

Palliative Medicine
27(6) 553–561

DOI: 10.1177/0269216312462272
pmj.sagepub.com
SAGE

Livia Anquinet *End-of-Life Care Research Group, Ghent University and Vrije Universiteit Brussel, Brussels, Belgium*
Kasper Raus *End-of-Life Care Research Group, Ghent University and Vrije Universiteit Brussel, Brussels, Belgium*
Sigrid Sterckx *End-of-Life Care Research Group, Ghent University and Vrije Universiteit Brussel, Brussels, Belgium*
Tinne Smets *End-of-Life Care Research Group, Ghent University and Vrije Universiteit Brussel, Brussels, Belgium*
Luc Deliens *End-of-Life Care Research Group, Ghent University and Vrije Universiteit Brussel, Brussels, Belgium; Department of Public and Occupational Health, EMGO Institute for Health and Care Research, VU University Medical Centre, Amsterdam, the Netherlands.*
Judith AC Rietjens *End-of-Life Care Research Group, Ghent University and Vrije Universiteit Brussel, Brussels, Belgium*

Abstract

Background: According to various guidelines about continuous sedation until death, this practice can and should be clearly distinguished from euthanasia, which is legalized in Belgium.

Aim: To explore professional caregivers' perceptions of the similarities and differences between continuous sedation until death and euthanasia.

Design: Qualitative data were gathered through focus groups. Questions pertained to participants' perceptions of continuous sedation. The focus groups were recorded and transcribed verbatim. Analyses were conducted by a multidisciplinary research team using constant comparison analyses.

Setting/Participants: We did four focus groups at Ghent University Hospital: two with physicians (n = 4 and n = 4) and two with nurses (n = 4 and n = 9). The participants could participate if they were ever involved in the use of continuous sedation until death.

Results: Although the differences and similarities between continuous sedation until death and euthanasia were not specifically addressed in the questions addressed in the focus groups, it emerged as an important theme in the participants' accounts. Many caregivers elaborated on the differences between both practices, particularly with regard to patients' preferences and requests, decision-making and physicians' intentions. However, some stated that the distinction between the two sometimes becomes blurred, especially when the sedating medication is increased disproportionally or when sedation is used for patients with a longer life expectancy.

Conclusions: The differences and similarities between continuous sedation until death and euthanasia is an issue for several Flemish professional caregivers in their care for unbearably suffering patients at the end of life. Although guidelines strictly distinguish both practices, this may not always be the case in Flemish clinical practice.

Introduction

In Belgium, numerous palliative care structures and services have been developed to provide high-quality care for terminally ill patients.[1] Yet, it is possible that patients in the final phase of their life suffer persistently and unbearably from refractory symptoms, that is, symptoms unresponsive to available treatment. According to various guidelines, in such cases, continuous sedation until death can be considered.[2,3] Continuous sedation refers to the practice where sedation, that is, the lowering of the patient's consciousness, is administered continuously until the time of death.[4]

Corresponding author:
Livia Anquinet, End-of-life Care Research Group, Ghent University and Vrije Universiteit Brussel, Laarbeeklaan 103, 1090 Brussels, Belgium.
Email: Livia.Anquinet@vub.ac.be

Continuous sedation can vary from mild to deep sedation.[2,3,5,6] In the Flemish region of Belgium in 2007, its incidence was estimated to be 14.5% of all deaths.[7] In the Netherlands, in 2005, continuous sedation was given in 8.2% of all deaths, and in the United Kingdom, in 2008, it was given in 16.5% of all deaths.[8–10]

Various guidelines state that continuous sedation at the end of life can only be performed when the patient has a very limited life expectancy.[2,3] Furthermore, they stress that continuous sedation should be distinguished from euthanasia – that is, the intentional ending of life by administering medication at the explicit request of a patient – explaining that continuous sedation is a way of proportionally alleviating the patients' refractory suffering and does not aim at the death of the patient.[11] In Belgium as well as in the Netherlands, given the fact that euthanasia is legalized,[11,12] the guidelines regarding sedation address the issue of the differences between continuous sedation and euthanasia. A nationwide Palliative Sedation guideline has been introduced in 2005 (and revised in 2009) in the Netherlands.[2] In Belgium, however, a guideline was introduced only recently (December 2010) and after we conducted our study.[3] The goal of our study was to explore the attitudes and experiences of physicians and nurses in Flanders with the practice of continuous sedation until death. We, therefore, conducted focus groups. The focus groups were conducted at the preliminary stage of a larger international interview study (the UNBIASED study – UK Netherlands Belgium International Sedation Study), aiming at exploring clinical decision-making surrounding the use of continuous sedation until death and understanding the beliefs, perceptions and experiences of (in)formal caregivers regarding this practice.[4]

In this article, we focus on the following research question: 'What do Flemish physicians and nurses perceive as similarities and differences between the practice of continuous sedation until death and the practice of euthanasia?'

Methods

Focus groups with professional caregivers were held in Flanders, Belgium, in April 2010. The main aim of the focus groups was to gain insight into the attitudes and experiences of professional caregivers regarding continuous sedation in end-of-life care.

Participants and setting

Physicians and nurses could participate in the focus groups if they had ever been involved in the use of continuous sedation until death. In order to obtain a broad range of multidisciplinary views and experiences, we included physicians and nurses from the home-care setting as well as the hospital setting (oncology ward and palliative care unit/palliative support team) in Flanders.

The participants were recruited in several ways. Contact information of potential participants was obtained through professional registries (the National Council of Physicians and the Belgian Society of Medical Oncology), the Federation for Palliative Care in Flanders, professional contacts of members of the research team and physicians who had already participated in previous studies of our research group. Invitations were sent by e-mail and through post. Follow-up phone calls were done by L.A. after 1 week.

Two focus groups were held with physicians and two with nurses. In all, 4–9 participants took part in each focus group. See Table 1 for their characteristics.

Procedures

The focus groups were held at Ghent University Hospital and lasted about 2 h. They were led by experienced moderators (L.D. and J.R., S.S. and J.R. or S.S. and R.D. (Prof. Dr. Reginald Deschepper, anthropologist and member of the End-of-Life Care Research Group)). Notes were made by two observers (L.A. and K.R.). All participants gave their informed consent to the audio taping of the discussions. The moderators used a topic guide, consisting of open questions and a brief set of prompts (Box 1). This topic guide covered several themes: (1) experiences of the participants with various types of sedation at the end of life, (2) attitudes regarding continuous sedation and (3) the medical situations in which continuous sedation is perceived to be more easy or difficult. Three vignettes were used to guide the discussion (Box 2). In each vignette, the presented patient had terminal breast cancer and suffered unbearably from untreatable physical symptoms despite receiving palliative care. The cases varied according to the patient's life expectancy (a few days vs 3–4 weeks), the performance of continuous sedation (deep sedation from the start vs titration of sedation according to symptoms) and the duration of the sedation (3 days vs 1 week). Socio-demographic characteristics were obtained from all participants (Table 1).

Data analysis

The recordings of the focus groups were transcribed verbatim, and all data that could identify the participants were removed to preserve anonymity. We performed constant comparative analyses. First, all transcripts were read several times by a multidisciplinary team of researchers (J.R., S.S., L.A., K.R. and L.D.). We identified the differences and similarities between continuous sedation and euthanasia as a major theme. We re-read all text fragments concerning this theme, and discussed, designed and agreed upon a coding tree. All the text fragments were coded independently by L.A. and K.R., and the codes were independently checked by J.R. and S.S. Differences in coding between the researchers were minimal, and a consensus was always reached. Qualitative analysis software (NVIVO 9) was used to organize the data. Finally, quotes were selected by

Table 1. Characteristics of focus group participants.

	Physicians (n = 8)		Nurses (n = 13)	
	Focus group 1 (n = 4)	Focus group 2 (n = 4)	Focus group 1 (n = 4)	Focus group 2 (n = 9)
Sex				
Male	1	3	1	4
Female	3	1	3	5
Age (years)				
30–39	0	1	0	0
40–49	2	0	1	5
50–59	2	2	3	3
60–69	0	0	0	1
≥70	0	1[a]	0	0
Setting				
Oncology ward	1	0	0	2
Palliative care unit	2	2	3	3
Home[b]	1	2	1	4
Experience with continuous sedation				
Yes	2	4	4	9
In the last year[c]	3	3–4[d]	1–4[e]	1–30[e]
In the professional career[c]	5[d]	2–50[d]	10–15[d]	3–15[d,e]
No	2	0	0	0

[a]85 years, retired.
[b]In the home-care settings, physicians included general practitioners, whether or not part of a palliative home-care team. Nurses in the home-care setting were always member of a palliative home-care team.
[c]The number of times physicians or nurses have had experience with continuous sedation until death.
[d]Missing: Focus group 1 physicians (in the professional career: n = 1); focus group 2 physicians (in the last year: n = 1; in the professional career: n = 1); focus group 1 nurses (in the professional career: n = 2); focus group 2 nurses (in the professional career: n = 3).
[e]Unknown: Focus group 1 nurses (in the last year: n = 1); focus group 2 nurses (in the last year: n = 1; in the professional career: n = 1).

Box 1. Topic guide of the focus groups with physicians and nurses.

Introduction

Part I: types of sedation (= kinds of sedation according to depth and duration of sedation)

1. Which types of sedation do you use for patients in their last phase of life? How do you define these?[a]

   Prompts: depth of sedation (deep, mild), duration of sedation (intermittent, continuous) and terms used.

Part II: understandings of and experiences with continuous sedation until death – vignettes

Vignettes of cases of continuous deep sedation until death are presented via Powerpoint.
Questions per vignette:

1. Which term best describes this act? Why?
2. Would you act in the same way? Why (not)?
3. Do you have any experience with other situations or circumstances in which patients are continuously sedated until death?

   Prompts: situations in which the patient was suffering from non-physical symptoms in which sedation was used as an alternative for euthanasia, or in which sedation was performed on request of the patient who wanted to die sleeping.

Part III: situations in which the use of sedation is more easy or more difficult

1. Are there situations in which the use of continuous sedation until death is more easy or more difficult for you?[b]

   Closing; answering questions; thanking the participants

[a]The questions for nurses were as follows: 'In which types of sedation for patients in their last phase of life have you been involved? How would you define these? How have you been involved in the performance of continuous sedation for a patient in her last phase of life?'.
[b]The question for nurses was as follows: 'Are there situations in which your involvement in the performance of continuous sedation until death is more easy or more difficult for you?'.

Box 2. Hypothetical clinical cases of continuous sedation.

Case 1

Patient A is a 72-year-old woman with metastatic breast cancer. She suffers from severe pain and anxiety. She is fatigued, and getting out of bed is becoming more and more difficult for her. Her life expectancy is estimated at a few days. A morphine drip proves insufficient relief for the pain and anxiety. There are no curative or life-prolonging treatment options available anymore, and the patient is receiving palliative care. The patient indicates to her physician that she cannot go on like this. She has a deep desire to sleep. It is decided to alleviate the patient's suffering as much as possible by administering midazolam until death. It is also decided not to administer artificial nutrition or hydration anymore. Midazolam is administered to bring the patient into a deep sleep. The patient no longer reacts to physical stimuli or when spoken to. The patient dies 3 days after the start of midazolam.

Case 2

Case 2 is similar to case 1 except that the doses of midazolam are matched to the severity of the symptoms. The patient lies there very peacefully, she is sleepy but still reacts when spoken to. The patient dies 3 days after the start of midazolam.

Case 3

Case 3 is similar to case 1 except that the patient has a life expectancy of 3–4 weeks. The patient dies 1 week after the start of midazolam.

L.A., K.R., J.R. and S.S. and translated by S.S. working with a native speaker.

Results

Differences between continuous sedation and euthanasia

Many participants reflected about the differences they perceived between continuous sedation and euthanasia, particularly in relation to patients' preferences and requests, decision-making and physicians' intentions.

Preferences and requests. Both physicians and nurses stressed the importance of good communication between everyone involved when they are confronted with a terminally ill patient who experiences great suffering and who indicates that he or she cannot bear it anymore. They considered it important to clarify the patient's wishes with respect to end-of-life decision-making. Physicians and nurses in our study indicated that they are rarely confronted with an explicit patient request for continuous sedation. In most cases, the patient's request was formulated in general terms, asking the physician to do something to relieve severe suffering. In contrast, patients requesting euthanasia were reported to generally use more specific formulations.

Several caregivers indicated that they discussed with the patient whether his or her wishes for the end of suffering included a desire for continuous sedation or a desire for euthanasia.

> Physician A; Home: When a patient says: 'I don't want to experience it anymore'. Well, that can be achieved with sedation or with euthanasia; does he want to sleep or does he want to die? So anyway, you need to talk about both.

> Nurse A; Home: First, we start by clarifying a request from a patient. If a patient says 'I don't want to experience the end anymore', then it is absolutely not clear to me what that patient wants. Does that man or woman want euthanasia or sedation? […] Once we have some insight as to what that patient is requesting, we then raise this issue with the attending physician, usually the General Practitioner. Sometimes we [the physician and the nurse] listen to the patient's request separately and then check with each other whether we have heard the same. Because for us, there is a strong distinction between putting someone to sleep and killing somebody by lethal injection.

The participants attributed the fact that continuous sedation was usually not requested in specific terms mostly to the fact that unlike the practice of euthanasia, this practice is not (well) known to the general public.

> Nurse B; Home: I think there are few patients who would ask: 'Now I want to be sedated'. They don't know the practice. I would say that the request [for continuous sedation] often comes from the family and caregivers, but very rarely from the patient.

Yet, sometimes, the patient's request for continuous sedation until death was very clear.

> Nurse C; Home: But there are also people who consciously choose not to have euthanasia, but who do indicate: 'If I experience symptoms that cannot be alleviated anymore, then I want sedation'.

After caregivers explained the differences between continuous sedation and euthanasia, patients often seemed to have different preferences for one practice or the other.

The respondents explained that some patients expressed a preference for continuous sedation over euthanasia because of spiritual reasons or also out of concern for his or her family. In the latter, the patient had a euthanasia request but had withdrawn this request.

> Nurse D; Palliative support team: And for various reasons, which could be spiritual, or with people who say 'I don't want euthanasia, but I don't want to suffer either, so when the time comes, please make sure that I am asleep'.

> Physician B; Palliative support team: For example, it can happen that a patient does want euthanasia, but knows that his wife, for instance, has difficulties with that. Such patients will say 'no, in that case, do something like sedation', simply out of respect or concern for their family, which would have a hard time coping afterwards [if euthanasia had been chosen].

In some cases, however, patients preferred euthanasia to continuous sedation because of the frightening thought of being unconscious for several days.

> Physician A; Home: And then there are patients who say 'yes, but if you put me to sleep and my body may have to lie here for another week or two …', then they recoil and some of them say 'in that case, give me euthanasia'.

For the physician, the possibility to comply with the patient's request for continuous sedation or euthanasia becomes more difficult when a discussion about these decisions is raised too late either by the physician or by the patient, or when no clear consensus can be reached between physician and patient.

> Physician A; Home: Those are the situations that we encounter most frequently in practice. Someone ends up in a hopeless situation, with no clear consensus having been reached with the patient in advance about the possibility of performing euthanasia, of performing a technique to shorten life. Sometimes this argument [that there was no clear consensus] is abused by colleagues of ours […] who have kept postponing [any discussion with the patient about euthanasia] and then of course, the patient ends up with her back against the wall and then the patient asks for euthanasia, but until then, they weren't listening to their patient and then they say 'yes, but now it is too late, because I can't arrange that [euthanasia] in such a short time'.

> Physician B; Palliative support team: What I sometimes experience is that [patients] know their end is getting near, and euthanasia, no no, that is not discussed or requested. And then suddenly, the symptoms become so unbearable and then they say: 'Yes but in fact, I want euthanasia'. But then you [the physician] are confronted with an acute situation and then you can't perform euthanasia anymore, because you need your own safety [in terms of respecting the legal requirements]. […] In such circumstances we move to palliative sedation because we say from a legal point of view we are not allowed to perform euthanasia, but we see that it is no longer bearable for the patient and it isn't medicine to leave the patient in an unbearable state, so the only thing we can do is initiate palliative sedation. Then we explain to the patient as well as to the family: […] this is no longer bearable for the patient, we can't bear to see this any longer, the only thing we can do now is put the patient to sleep, but in a way that the rest of the process will follow a natural course, and how long that will take, well we don't know.

Not all patients had specific preferences for one practice or the other when the differences between both practices were explained to them. As illustrated by a physician:

> Physician A; Home: That often happens in practice in my experience, that when you talk to people about the possibilities [at the end of life], patients will often reply: 'Just act for the best and make sure I don't suffer'. Of course, this is not the same as having a patient say: 'I want euthanasia'.

Decision-making. Both physicians and nurses mentioned to be reluctant to use continuous sedation for patients with a longer life expectancy, whereas this was not necessarily regarded as a problem for patients requesting euthanasia.

> Physician A; Home: For euthanasia, the patient can still have a life expectancy of weeks, months, or even years. You can have cancer patients who may still have months to live […]. In these cases, we would not perform palliative sedation.

Concerning the actual decision-making, some nurses in our focus groups stated that compared with cases of euthanasia, physicians less often included nurses in the decision-making regarding continuous sedation.

> Nurse F; Oncology: In our hospital I have observed that when we talk about euthanasia, it is always discussed by the team. […] And everyone can give their input, whereas when we are talking about palliative sedation, the decision is often taken by the physician […]. When we talk about euthanasia, we [nurses] are involved in the decision-making, so it is strange that when palliative sedation is at issue, not a single nurse on the ward finds it odd that she is not involved.

A nurse explained that this may have to do with a lack of official procedures and guidelines for continuous sedation, combined with an unwillingness of certain physicians to consult others in their decision-making:

> Nurse A; Home: The euthanasia procedure provides that a physician should consult with the nursing team and with the family, whereas for palliative sedation, there are no

procedures, there are no guidelines. So it is precisely the profile of very dominant and hierarchical physicians that matches very well with palliative sedation, because there they hold absolute sway and they don't have to consult with anyone. So it is true that there is a certain kind of physician who chooses not to perform euthanasia, but performs palliative sedation instead: 'we will quietly increase the dose'. In our team we call those patients a 'sans papier' [i.e. and undocumented person, a term used for illegal aliens]. You don't have a procedure, you don't have to report anything, and it's all okay and the problem is solved.

Intention. Finally, many physicians and nurses drew a clear distinction between continuous sedation and euthanasia with regard to the intention involved. They explained that sedation aims to control refractory symptoms, whereas in the case of euthanasia one has the intention to end the patient's life.

Nurse E; Palliative support team: Everyone is always talking about an intention. Thus, sedation does not have the intention to kill, but to control refractory symptoms, whereas euthanasia has the intention to kill.

Physician C; Palliative support team: You don't initiate sedation to shorten [a patient's] life, that is never an intention of … [palliative sedation].

Physician A; Home: Indeed, that is precisely the reason why you have to perform it in the last phase and not for patients who are suffering from symptoms but who are still eating and drinking. Patients who continue to eat and drink, may live for another month or two.

Physician B; Palliative support team: [W]hen you start palliative sedation, [the] comfort of your patient […] is your only intention.

When the distinction between continuous sedation and euthanasia may become blurred

Although the majority of the respondents considered continuous sedation and euthanasia as different practices at the end of life, some stated that the distinction between the two may become blurred, conceptually or ethically.

Nurse F; Oncology: I'm always struggling with this. The transition. When do we talk about euthanasia, and when about sedation?

Nurse G; Home: No, euthanasia, that is clear … that is very clear.

Nurse F; Oncology: I don't know, for me it is not so clear. I find it a bit eh …

Nurse G; Home: Euthanasia is really […] where someone is […] giving a lethal injection at the request of the patient. Whereas sedation is just keeping someone asleep until maybe death follows.

Physician B; Palliative support team: Whether you perform sedation or euthanasia, ethically speaking that is the same for me … I would cover myself and take the same measures and follow the same procedures for sedation as I would for euthanasia. When performing sedation, a physician should not delude herself into thinking 'since it is sedation I am administering, there cannot be any problems'. I would want to rely on various people's advice that sedation is indeed appropriate in the case at hand, before initiating it. From an ethical point of view, it is exactly the same action … initiating a euthanasia or a sedation is the same, ethically speaking.

According to the respondents, the distinction between continuous sedation and euthanasia diminishes or may even disappear when medication is increased disproportionally. Some participants described that the intention shifted to the ending of life.

Nurse H; Palliative care unit: What I have observed in the context of my work in the [palliative] support team is that usually, from the start, a thorough sedation was given. Sedation was frequently started with the understanding: 'If the patient is still here tomorrow, then we will double [the dose]'. That was commonplace. So in fact they often ended life, even if this was not the initial intention of the sedation. [The underlying reasoning seemed to be:] since the patient is not awake anymore, what is the point of letting her lie here for days?

Nurse A; Home: That is one of the sore points. There is a strong temptation to increase the dose until the sedation is no longer proportional to the refractory symptoms, and then you are probably shortening life.

Nurse I; Home: [I] think: 'Darn, we are doing it [increasing the dose] and it happens all the time in practice. And that is very difficult for me. What do you have to do about the team? How can the team cope with the fact that yesterday the pump was on such and such a dose but today it is at a higher dose.

Nurse J; Palliative support team: If it is agreed in advance that we will increase, increase, increase the dose until the patient dies, then what is happening is not attempting to control the symptoms and allowing the patient to die. The intention then is to end life.

A physician described another situation in which sedation might shorten life, namely, when sedation is induced for patients with a longer life expectancy.

Physician A; Home: But if one performs it too early in the course of a disease, then one is shortening life.

Discussion

Although the differences and similarities between continuous sedation until death and euthanasia were not specifically addressed in the questions in the focus groups, it emerged as an important theme in the accounts of the participants. Our study describes the similarities and differences between both practices as perceived by physicians and nurses in Flanders, Belgium. Sometimes, the term 'euthanasia' was used by both groups as an umbrella term, also including acts of life ending without a request of the patient. Many participants perceived differences between continuous sedation and euthanasia, particularly with regard to preferences and requests, decision-making and intention. However, some participants stated that the distinction between the two is sometimes blurred or even nonexistent, especially when medication is increased disproportionally or when sedation is induced too early.

Our study is one of the few studies that provide in-depth insight into physicians' and nurses' attitudes and experiences regarding the practice of continuous sedation until death. Our study benefited from the use of focus groups allowing us to explore knowledge, views and beliefs about two end-of-life practices that are subjects of medical and ethical discussion. Through focus groups, it is also possible to obtain multiple perspectives about the same topic of research by inviting participants from different backgrounds and settings. However, this research method entails some limitations. In view of the small numbers of participants and the fact that these participants do not constitute a representative sample, our findings cannot be generalized to the whole population of physicians and nurses. Furthermore, focus groups are not fully anonymous since opinions and experiences are shared with the group as a whole. The sensitivity of the topic of our focus groups might have led to socially desirable answers by the participants and participants being more reluctant to state their true opinions. We have tried to overcome this issue as much as possible by stressing confidentiality. Finally, respondents' terminology did not always correspond with the definitions of the researchers, nor with those of the Belgian Euthanasia Law, and the term 'euthanasia' sometimes also referred to acts of life ending without a request of the patient. This should be taken into account when interpreting our findings.

Euthanasia was legalized in Belgium in 2002 after more than a decade of intense societal debate galvanized by an opinion on euthanasia from the Belgian Advisory Committee on Bioethics as well as 3 years of debate in parliament.[11] This end-of-life practice has increasingly been brought to the attention of caregivers and the general public, also by way of the media, and to this day, it remains an important issue of public debate.[13] According to our participants, patients requesting euthanasia generally used more specific formulations, whereas continuous sedation was less often or less explicitly addressed by patients. It is possible that the practice of continuous sedation until death is less well known among patients and their environment. Furthermore, it may also relate to the fact that a key condition for euthanasia is that the patient should make an explicit request, while such a request is not a prerequisite for the use of continuous sedation until death (although guidelines state that its use should be discussed with a competent patient or his or her representatives). Despite the fact that patients' and families' wishes were not always expressed clearly or specifically, the participants in our study stated that they deemed it important to clarify these wishes and preferences through ample communication and discussion.

Besides the importance of discussing such far-reaching end-of-life decisions with the patient, consultation and discussion with other caregivers are deemed important too. For euthanasia, the physician must consult with a second independent physician as well as with the nursing team, if applicable.[12] Various guidelines on sedation state that the members of the team involved in the care for the patient should be actively involved in decision-making.[2,3] If a physician doubts his or her own expertise concerning continuous sedation or finds it difficult to decide whether or not to initiate continuous sedation, the physician should seek specialist palliative care advice. Nurses in our study reported to be less often involved in decision-making for continuous sedation than for euthanasia. This is in line with the findings from another Belgian study: Inghelbrecht et al.[14] found that there was no communication between the nurse and the physician about continuous deep sedation in 17.6% of the sedation cases.

Although the majority of the respondents in our study considered continuous sedation and euthanasia as different practices at the end of life, some stated that the clear distinction between continuous sedation and euthanasia diminishes or may even disappear when medication is increased disproportionally or when sedation is induced too early. Some respondents described that in such instances, the physicians' intention is or shifts to life ending. The focus group participants thus often considered the intention with which the action is performed as well as the outcome pivotal in distinguishing continuous sedation from euthanasia, which is in line with the argumentation developed in Materstvedt.[15] The finding that some respondents did not always find sedation and euthanasia to be clearly distinguishable is also in line with other studies. In a study of Rietjens et al.,[16] some American nurses had difficulties with working on a 'fine line' between sedation and euthanasia. According to them, sedating a patient diminishes the patient's capacity to eat and drink, and as such will contribute to their death. A study concerning general practitioners of Anquinet et al.[17] revealed that 2 out of 28 physicians perceived the use of continuous deep sedation as similar to euthanasia. This was the case when the patient had

previously made a request for euthanasia. Other studies have also shown that physicians sometimes also administer sedatives when they intend to end life.[7,18] An international study of Anquinet et al.[8] that compared the practice of continuous deep sedation in Belgium, the Netherlands and the UK, found that in several cases, physicians who had indicated that they had performed continuous deep sedation until death also indicated that they had done so to end the patient's life. However, these studies do not report on the types and dosages of drugs administered during the performance of continuous deep sedation until death. Because it is known from studies about the effect of morphine on patients' life expectancy that physicians might overestimate the life-shortening effect of such medications[19] these studies should be interpreted cautiously.

Guidelines distinguish the use of continuous sedation until death from drug-induced ending of life (this is referred to as euthanasia in the case of an explicit patient request) by referring to the physicians' intention as well as to the outcomes of the physicians' acts, therefore referring to similar concepts as our focus group respondents. More specifically, the guidelines state that the physician's intention while applying continuous sedation should be to relieve suffering through the lowering of consciousness, while the physician's intention while applying euthanasia is to relieve suffering through the ending of life by the administration of a lethal dose of medication.[2,3] They further state that 'the physician's act should reflect this intention, meaning that the dosages and combinations of medication should be administered in proportion to the specific suffering of the patient that the physician wants to alleviate'.[3] In addition, the guidelines say that 'there is no evidence that sedation, if carried out in accordance with good medical practice, does shorten life, while euthanasia certainly does'.[2] Therefore, they state that sedation can only be used for patients with a life expectancy of at most a few days to 1 week (Belgian guideline) or to 2 weeks (Dutch guideline) because otherwise patients would die as a result of the sedation, that is, through dehydration, since both guidelines recommend to withdraw the administration of artificial hydration when this is considered to be medically futile.[2,3]

We want to point to two caution remarks here. First, on the basis of our qualitative data, we cannot draw conclusions on the frequency of physicians' use of sedation with the intention or the outcome of shortening life. Second, there is ample ethical debate and no clear consensus about the differences and similarities between sedation and euthanasia, and several authors claim different borders.[15,20] In this article, we describe the experiences and attitudes of our focus group respondents. Having said that, it is clear that the situations described by the respondents are clearly not always in line with guideline recommendations.[2,3] This might, in part, be explained by a lack of knowledge about the circumstances in which sedation can be used as well as the way it should be performed properly. The Belgian sedation guideline has been published in September 2010, after the performance of our focus group study. Moreover, it is possible that physicians perceive continuous sedation as part of regular medical treatment, and therefore, for example, do not feel obliged to talk the decision for sedation through, for example, with nurses involved in the care for the patient or palliative care expert teams.

Our findings may have some practical implications. Safeguards with regard to decision-making on continuous sedation may be necessary for clinical practice. The practice of continuous sedation and its appropriate performance should be included and extensively discussed in medical training for physicians as well as for nurses, and guidelines could also play an important role in achieving these goals. In addition, future in-depth research should be concerned with what types and dosages of medications are being used in continuous sedation, the indications for such treatment, and should address the issue of the potential life-shortening effect of such sedative medicines. Our qualitative data on the differences, but most important, on the similarities between continuous sedation and euthanasia as perceived by professional caregivers may be relevant to other countries, also countries where euthanasia is illegal. In those countries, professional caregivers might experience similar struggles as the respondents in our study. It would be interesting to explore in further international research whether our findings could be extrapolated to other countries in general and to countries without a euthanasia law more specifically. Finally, in-depth and international research from multiple perspectives (also relatives) should also be encouraged to provide a better understanding of the practice of continuous sedation until death.

Acknowledgments

The authors would like to thank all the physicians and nurses who participated in the focus groups and Prof. Dr Reginald Deschepper for his cooperation as a moderator in one of the focus groups of this study. We further thank the Federation for Palliative Care Flanders, and in particular Trudie van Iersel, for their advice in recruiting participants for our focus groups.

Conflict of interest

The authors declare that there is no conflict of interest.

Funding

The research on which this article is based is linked to a larger project, the 'UNBIASED' study (UK – Netherlands – Belgium InternAtional SEDation study), which is a collaboration between research teams in the United Kingdom, Belgium and the Netherlands with funding from the Economic and Social Research Council (UK; grant no: RES-062-23-2078), Research Foundation Flanders (Belgium), the Flemish Cancer Association (Belgium), the Special Research Funds of the University of Ghent (Belgium),

Netherlands Organisation for Scientific Research (Netherlands) and the Netherlands Organisation for Health Research and Development (Netherlands). For information, contact Professor Jane Seymour: jane.seymour@nottingham.ac.uk.

References

1. Keirse E, Beguin C, Desmedt M, et al. *Organisatie van palliatieve zorg in België. Health Services Research (HSR)*. KCE reports 115A (D/2009/10.273/40), 2009. Brussels: Federaal Kenniscentrum voor de Gezondheidszorg (KCE) (accessed November 2011).
2. Royal Dutch Medical Association (KNMG). Guideline for palliative sedation, http://knmg.artsennet.nl/Publicaties/KNMG publicatie/Guideline-for-palliative-sedation-2009.htm, 2009.
3. Broeckaert B, Mullie A, Gielen J, et al. Richtlijn palliatieve sedatie, http://www.pallialine.be/template.asp?f=rl_sedatie.htm, 2010.
4. Seymour J, Rietjens J, Brown J, et al. The perspectives of clinical staff and bereaved informal care-givers on the use of continuous sedation until death for cancer patients: the study protocol of the UNBIASED study. *BMC Palliat Care* 2011; 10: 5.
5. De Graeff A and Dean M. Palliative sedation therapy in the last weeks of life: a literature review and recommendations for standards. *J Palliat Med* 2007; 10: 67–85.
6. Swart SJ, van der Heide A, van Zuylen L, et al. Considerations of physicians about the depth of palliative sedation at the end of life. *CMAJ* 2012; 184: E360–366.
7. Chambaere K, Bilsen J, Cohen J, et al. Continuous deep sedation until death in Belgium: a nationwide survey. *Arch Intern Med* 2010; 170: 490–494.
8. Anquinet L, Rietjens J, Seale C, et al. The practice of continuous deep sedation until death in Flanders (Belgium), the Netherlands and the United Kingdom: a comparative study. *J Pain Symptom Manage* 2012; 44: 33–43.
9. Rietjens JAC, van Delden JJM, Onwuteaka-Philipsen B, et al. Continuous deep sedation for patients nearing death in the Netherlands: descriptive study. *BMJ* 2008; 336: 810–813.
10. Seale C. End-of-life decisions in the UK involving medical practitioners. *Palliat Med* 2009; 23: 198–204.
11. Deliens L and van der Wal G. The euthanasia law in Belgium and the Netherlands. *Lancet* 2003; 362: 1239–1240.
12. The Belgian Act on Euthanasia of May, 28th 2002, http://www.kuleuven.be/cbmer/viewpic.php?LAN=E&;TABLE=DOCS&ID=23. 28-5-2002
13. Meeussen K, Van den Block L, Bossuyt N, et al. Dealing with requests for euthanasia: interview study among general practitioners in Belgium. *J Pain Symptom Manage* 2011; 41: 1060–1073.
14. Inghelbrecht E, Bilsen J, Mortier F, et al. Continuous deep sedation until death in Belgium: a survey among nurses. *J Pain Symptom Manage* 2011; 41: 870–879.
15. Materstvedt LJ. Intention, procedure, outcome and personhood in palliative sedation and euthanasia. *BMJ Support Palliat Care* 2012; 2: 9–11.
16. Rietjens JAC, Hauser J, van der Heide A, et al. Having a difficult time leaving: experiences and attitudes of nurses with palliative sedation. *Palliat Med* 2007; 21: 643–649.
17. Anquinet L, Rietjens JAC, Van den Block L, et al. General practitioners' report of continuous deep sedation until death for patients dying at home: a descriptive study from Belgium. *Eur J Gen Prac* 2011; 17: 5–13.
18. Rietjens JAC, van der Heide A, Vrakking AM, et al. Physician reports of terminal sedation without hydration or nutrition for patients nearing death in the Netherlands. *Ann Intern med* 2004; 141: 178–185.
19. Morita T, Tsunoda J, Inoue S, et al. Effects of high dose opioids and sedatives on survival in terminally ill cancer patients. *J Pain Symptom Manage* 2001; 21: 282–289.
20. Rady MY and Verheijde JL. Continuous deep sedation until death: palliation or physician-assisted death? *Am J Hosp Palliat Care* 2010; 27: 205–214.