

1 **Continuous sedation until death not always strictly distinguished from euthanasia.**

2 **A focus group study in Flanders, Belgium**

3

4 **Livia Anquinet¹, Kasper Raus¹, Sigrid Sterckx¹, Tinne Smets¹, Luc Deliens^{1,2}, Judith**
5 **Rietjens¹**

6 **[ACCEPTED FOR PUBLICATION IN THE JOURNAL PALLIATIVE MEDICINE]**

7

8 ¹End-of-Life Care Research Group, Ghent University & Vrije Universiteit Brussel, Brussels,
9 Belgium.

10 ²Department of Public and Occupational Health, EMGO Institute for Health and Care Research,
11 VU University Medical Centre, Amsterdam, the Netherlands.

12

13 *Address for correspondence*

14 Livia Anquinet, End-of-life Care Research Group, Ghent University & Vrije Universiteit
15 Brussel, Laarbeeklaan 103, 1090 Brussels, Belgium. Telephone: +32 (0)2 477 47 53. Fax: +32
16 (0)2 477 47 11. E-mail: Livia.Anquinet@vub.ac.be

17

18

19

1

2 **ABSTRACT**

3 **Context**

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

6 **Objectives**

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

9 **Methods**

10 Qualitative data were gathered through four focus groups: two with physicians (n=4&n=4) and
11 two with nurses (n=4&n=9). Participants could participate if they were ever involved in the use
12 of continuous sedation until death. Questions pertained to participants' attitudes of and
13 experiences with the use of continuous sedation. The focus groups were recorded and transcribed
14 verbatim. Analyses were conducted by a multidisciplinary research team using constant
15 comparison analyses.

16 **Results**

17 Although the differences and similarities between continuous sedation until death and euthanasia
18 were not specifically addressed in the questions addressed in the focus groups, it emerged as an
19 important theme in participants' accounts. Many participants elaborated on the differences
20 between both practices, particularly as regards to patients' preferences and requests, decision-

1 making, and physicians' intentions. However, some participants stated that the distinction
2 between the two sometimes becomes blurred, especially when the sedating medication is
3 increased disproportionately or when sedation is used for patients with a longer life expectancy.

4 **Conclusion**

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

9

10 **Key words:** Continuous sedation until death; euthanasia; attitudes; focus groups; physicians;
11 nurses; end-of-life care.

12

13

14

15

16

17

18

19

1

2 INTRODUCTION

3 In Belgium, numerous palliative care structures and services have been developed to provide
4 high quality care for terminally ill patients (1). Yet it is possible that patients in the final phase of
5 their life suffer persistently and unbearably from refractory symptoms, i.e. symptoms
6 unresponsive to available treatment. According to various guidelines, in such cases, continuous
7 sedation until death can be considered (2;3). Continuous sedation refers to the practice where
8 sedation, i.e. the lowering of the patient's consciousness, is administered continuously until the
9 time of death (4). In the Flemish region of Belgium in 2007, its incidence was estimated to be
10 14.5% of all deaths (5).

11 Various guidelines state that continuous sedation at the end of life can only be performed when
12 the patient has a very limited life expectancy (2;3). Further, they stress that continuous sedation
13 should be distinguished from euthanasia -i.e. the intentionally ending of life at the explicit
14 request of a patient-, explaining that continuous sedation is a way of proportionally alleviating
15 the patients' refractory suffering and does not aim at the death of the patient (6). In Belgium as
16 well as in the Netherlands, given the fact that euthanasia is legalized (6;7), the guidelines
17 regarding sedation address the issue of the differences between continuous sedation and
18 euthanasia.

19 The goal of our study was to explore the attitudes and experiences of physicians and nurses in
20 Flanders with the practice of continuous sedation until death. We therefore conducted focus
21 groups. The focus groups were conducted at the preliminary stage of a larger international
22 interview study (the UNBIASED study - UK Netherlands Belgium International Sedation

1 Study), aiming at exploring clinical decision-making surrounding the use of continuous sedation
2 until death and understanding the beliefs, perceptions and experiences of (in)formal caregivers
3 regarding this practice (4).

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

7

8

9

10

11

12

13

14

15

16

17

18

1

2 **METHODS**

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

6 *Participants and setting*

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

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

17 Two focus groups were held with physicians and two with nurses. Four to nine participants took
18 part in each focus group. See Table 1 for their characteristics.

19 *Procedures*

1 The focus groups were held at Ghent University Hospital and lasted about two hours. They were
2 led by experienced moderators (LD & JR, SS & JR or SS & RD¹). Notes were made by two
3 observers (LA & KR). All participants gave their informed consent to the audio taping of the
4 discussions. The moderators used a topic guide, consisting of open questions and a brief set of
5 prompts (Box 1). This topic guide covered several themes: 1) experiences of the participants
6 with various types of sedation at the end of life; 2) attitudes regarding continuous sedation; and
7 3) the medical situations in which continuous sedation is perceived to be more easy or difficult.
8 Three vignettes were used to guide the discussion (Box 2). In each vignette, the presented patient
9 had terminal breast cancer and suffered unbearably from untreatable physical symptoms despite
10 receiving palliative care. The cases varied according to the patient's life expectancy (a few days
11 versus 3 to 4 weeks), the performance of continuous sedation (deep sedation from the start versus
12 titration of sedation according to symptoms) and the duration of the sedation (3 days versus 1
13 week). Socio-demographic characteristics were obtained from all participants (Table 1).

14 *Data analysis*

15 The recordings of the focus groups were transcribed verbatim and all data that could identify the
16 participants were removed to preserve anonymity. We performed constant comparative analyses.
17 First, all transcripts were read several times by a multidisciplinary team of researchers (JR, SS,
18 LA, KR, LD). We identified the differences and similarities between continuous sedation and
19 euthanasia as a major theme. We reread all text fragments concerning this theme, and discussed,
20 designed and agreed upon a coding tree. All the text fragments were coded independently by LA
21 and KR and the codes were independently checked by JR and SS. Differences in coding between

¹ RD: Prof. Dr. Reginald Deschepper, anthropologist and member of the End-of-Life Care Research Group.

1 the researchers were minimal and a consensus was always reached. Qualitative analysis software
2 (NVIVO 9) was used to organize the data. Finally, quotes were selected by LA, KR, JR and SS,
3 and translated by SS working with a native speaker.

4 **RESULTS**

5 **Differences between continuous sedation and euthanasia**

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

9 *Preferences and requests*

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

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

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

4

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

13

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

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

20

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

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

4

5

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

8 Respondents explained that some patients expressed a preference for continuous sedation over
9 euthanasia because of spiritual reasons, but in the case of a euthanasia request by the patient also
10 out of concern for his/her family .

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

14

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

19

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

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

6

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

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

20

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

14

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

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

21

22 *Decision-making*

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

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

7

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

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

17

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

1 *Nurse A; Home: The euthanasia procedure provides that a physician should consult with*
2 *the nursing team and with the family, whereas for palliative sedation, there are no*
3 *procedures, there are no guidelines. So it is precisely the profile of very dominant and*
4 *hierarchical physicians that matches very well with palliative sedation, because there they*
5 *hold absolute sway and they don't have to consult with anyone. So it is true that there is a*
6 *certain kind of physician who chooses not to perform euthanasia, but performs palliative*
7 *sedation instead: "we will quietly increase the dose". In our team we call those patients a*
8 *"sans papier" [i.e. and undocumented person, a term used for illegal aliens]. You don't*
9 *have a procedure, you don't have to report anything, and it's all okay and the problem is*
10 *solved.*

11

12 *Intention*

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

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

20

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

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

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

8

9 **When the distinction between continuous sedation and euthanasia may become blurred**

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

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

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

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

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

20

1 *Physician B; Palliative support team: Whether you perform sedation or euthanasia,*
2 *ethically speaking that is the same for me... I would cover myself and take the same*
3 *measures and follow the same procedures for sedation as I would for euthanasia.*

4

5 According to the respondents, the distinction between continuous sedation and euthanasia
6 diminishes or may even disappear when medication is increased disproportionately or when
7 sedation is induced too early.

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

15

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

19

20 *Nurse I; Home: [I] think: “Darn, we are doing it [increasing the dose] and it happens all*
21 *the time in practice. And that is very difficult for me. What do you have to do about the*

1 *team? How can the team cope with the fact that yesterday the pump was on such and such*
2 *a dose but today it is at a higher dose.*

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

6
7 *Nurse I; Home: We have had a case where a sedated patient lived on for three and a half*
8 *weeks. That is not humane, that is not tolerable. No way.*

9 *Nurse K; Home: Indeed. We apply the Dutch guidelines, so a prognosis of 14 days and no*
10 *more. Admittedly, there can be mistakes but...*

11
12 *Physician A; Home: But if one performs it too early in the course of a disease, then one is*
13 *shortening life.*

14

15

16

17

18

19

20

21

1

2

3

4

5

6 **DISCUSSION**

7 Although the differences and similarities between continuous sedation until death and euthanasia
8 were not specifically addressed in the questions in the focus groups, it emerged as an important
9 theme in the accounts of the participants. Our study describes the similarities and differences
10 between both practices as perceived by physicians and nurses in Flanders, Belgium. Many
11 participants perceived differences between continuous sedation and euthanasia, particularly with
12 regard to preferences and requests, decision-making, and intention. However, some participants
13 stated that the distinction between the two is sometimes blurred or even non-existent, especially
14 when medication is increased disproportionately or when sedation is induced too early.

15 *Strengths and limitations of the study*

16 Our study is one of the few studies that provide in-depth insight into physicians' and nurses'
17 attitudes and experiences regarding the practice of continuous sedation until death. Our study
18 benefitted from the use of focus groups allowing us to explore knowledge, views and beliefs
19 about two end of life practices that are subjects of medical and ethical discussion. Through focus
20 groups, it is also possible to obtain multiple perspectives about the same topic of research by
21 inviting participants from different backgrounds and settings. However, this research method

1 entails some limitations. In view of the small numbers of participants and the fact that these
2 participants do not constitute a representative sample, our findings cannot be generalized to the
3 whole population of physicians and nurses. Furthermore, focus groups are not fully anonymous
4 since opinions and experiences are shared with the group as a whole. The sensitivity of the topic
5 of our focus groups might have led to socially desirable answers by the participants and
6 participants being more reluctant to state their true opinions. We have tried to overcome this
7 issue as much as possible by stressing confidentiality.

8 Euthanasia was legalized in Belgium in 2002 after more than a decade of intense societal debate
9 galvanized by an opinion on euthanasia from the Belgian Advisory Committee on Bioethics as
10 well as three years of debate in parliament (6). This end-of-life practice has increasingly been
11 brought to the attention of caregivers and the general public, also by way of the media, and to
12 this day, it remains an important issue of public debate (8). According to our participants,
13 patients requesting euthanasia generally used more specific formulations, whereas continuous
14 sedation was less often or less explicitly addressed by patients. It is possible that the practice of
15 continuous sedation until death is less well-known among patients and their environment.
16 Furthermore, it may also relate to the fact that a key condition for euthanasia is that the patient
17 should make an explicit request, while such a request is not a prerequisite for the use of
18 continuous sedation until death (although guidelines state that its use should be discussed with a
19 competent patient or his/her representatives). Despite the fact that patients' and families' wishes
20 were not always expressed clearly or specifically, the participants in our study stated that they
21 deemed it important to clarify these wishes and preferences through ample communication and
22 discussion.

1 Besides the importance of discussing such far-reaching end-of-life decisions with the patient,
2 consultation and discussion with other caregivers is deemed important too. For euthanasia, the
3 physician must consult with a second independent physician as well as with the nursing team if
4 applicable (7). Various guidelines on sedation state that the members of the team involved in the
5 care for the patient should be actively involved in decision-making (2;3). If a physician doubts
6 his/her own expertise concerning continuous sedation or finds it difficult to decide whether or
7 not to initiate continuous sedation, the physician should seek specialist palliative care advice.
8 Nurses in our study reported to be less often involved in decision-making for continuous sedation
9 than for euthanasia. This is in line with the findings from another Belgian study: Inghelbrecht et
10 al. found that there was no communication between the nurse and the physician about continuous
11 deep sedation in 17.6% of the sedation cases (9).

12 Guidelines about continuous sedation until death distinguish this practice from the active ending
13 of life such as euthanasia by stating that for continuous sedation the intention is to relieve
14 suffering through lowering of consciousness, while euthanasia is used to end suffering through
15 the termination of life (2;3). Furthermore, they state that the situations in which both practices
16 are used do not necessarily coincide (2;3). For example, while it is advised that continuous
17 sedation should only be used for patients with a limited life-expectancy, this is not a necessary
18 precondition for euthanasia. Although the majority of the respondents in our study considered
19 continuous sedation and euthanasia as different practices at the end of life, some stated that the
20 clear distinction between continuous sedation and euthanasia diminishes or may even disappear
21 when the sedation is increased disproportionally or when sedation is induced too early. Our
22 finding is in line with other studies. In a study of Rietjens et al., some nurses had difficulties with
23 working on a 'fine line' between sedation and euthanasia (10). According to them, sedating a

1 patient and thus lowering her consciousness diminishes the patient's capacity to communicate,
2 eat and drink, and, in some cases, live. A study concerning general practitioners of Anquinet et
3 al. revealed that 2 out of 28 physicians perceived the use of continuous deep sedation as similar
4 to euthanasia (11). In 13/28 cases, the general practitioner indicated that hastening the patient's
5 death was his/her main intention or one of his/her intentions. Other quantitative studies showed
6 similar results: Chambaere et al. found that there was a (co-)intention of the physician to hasten
7 death in 17% of the sedation cases (5); hastening death was also an explicit intention in 17% of
8 the cases and partly the intention in 47% of the cases in a Dutch survey by Rietjens et al. (12).
9 An international study of Anquinet et al. that compared the practice of continuous deep sedation
10 in Belgium, the Netherlands and the UK, found that sedation was in some cases performed in
11 conjunction with physician-assisted dying (13).

12 These findings may have some practical implications. A Belgian sedation guideline has been
13 published in September 2010, after the performance of our focus group study (3). Our study
14 shows that sometimes a discrepancy exists between guidelines' recommendations and actual
15 practice. This might in part be explained by a lack of knowledge about the circumstances in
16 which sedation can be used as well as the way it should be performed properly. Also, it is
17 possible that physicians perceive continuous sedation as part of regular medical treatment and
18 therefore, for example, do not feel obliged to talk the decision for sedation through with the
19 nurses involved in the care for the patient. Safeguards with regard to decision-making on
20 continuous sedation may be necessary for clinical practice. The practice of continuous sedation
21 and its appropriate performance should be included and extensively discussed in medical training
22 for physicians as well as for nurses and guidelines could also play an important role in achieving
23 these goals. This study was performed in a country where euthanasia is legal. It would be

1 interesting to explore in further international research whether our findings could be extrapolated
2 to other countries in general and to countries without a euthanasia law more specifically. Further
3 in-depth and international research from multiple perspectives (also relatives) should also be
4 encouraged to provide a better understanding of the practice of continuous sedation until death.

5 *Disclosures and acknowledgements*

6 Funding

7 The research on which this paper is based is linked to a larger project, the 'UNBIASED' study
8 (UK - Netherlands - Belgium InternAtional SEDation study), which is a collaboration between
9 research teams in UK, Belgium and the Netherlands with funding from the Economic and Social
10 Research Council (UK) (grant no: RES-062-23-2078), Research Foundation Flanders (BE), the
11 Flemish Cancer Association (BE), the Special Research Funds of the University of Ghent (BE),
12 Netherlands Organisation for Scientific Research (NL) and the Netherlands Organisation for
13 Health Research and Development (NL). For information, contact Professor Jane Seymour:
14 jane.seymour@nottingham.ac.uk.

15 Competing interests

16 The authors have stated that there are no conflicts of interests.

17 Acknowledgments

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

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18

Reference List

(1) Keirse E, Beguin C, Desmedt M, et al. Organisatie van palliatieve zorg in België. Health Services Research (HSR). Brussel: Federaal Kenniscentrum voor de Gezondheidszorg (KCE). KCE reports 115A (D/2009/10.273/40); 2009.

(2) Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst. KNMG-richtlijn palliatieve sedatie. Utrecht: 2009.

(3) Broeckaert B, Mullie A, Gielen J, Desmet M, Vanden Berghe P. Richtlijn palliatieve sedatie. www.palliatief.be . 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 Pall Care 2011;10(1):5.

(5) Chambaere K, Bilsen J, Cohen J, et al. Continuous deep sedation until death in Belgium: a nationwide survey. Arch Intern Med 2010;170:490-4.

- 1 (6) Deliens L, van der Wal G. The euthanasia law in Belgium and the Netherlands. *Lancet*
2 2003 Oct 11;362(9391):1239-40.
- 3 (7) *Wet betreffende euthanasie 28 mei, 2002. Belgisch Staatsblad 22 juni 2002* [Law
4 concerning euthanasia May 28, 2002. Belgian official collection of the Laws 22 June
5 2002]. <http://www.health.fgov.be/euthanasie> . 2011.
- 6 (8) Meeussen K, Van den Block L, Bossuyt N, et al. Dealing with requests for euthanasia:
7 Interview study among general practitioners in Belgium. *J Pain Symptom Manage*
8 2011;41(6):1060-73.
- 9 (9) Inghelbrecht E, Bilsen J, Mortier F, Deliens L. Continuous deep sedation until death in
10 Belgium: A survey among nurses. *J Pain Symptom Manage* 2011;41(5):870-9.
- 11 (10) Rietjens JAC, Hauser J, van der Heide A, Emanuel L. Having a difficult time leaving:
12 Experiences and attitudes of nurses with palliative sedation. *Pall Med* 2007;21(7):643-9.
- 13 (11) Anquinet L, Rietjens JAC, Van den Block L, Bossuyt N, Deliens L. General practitioners'
14 report of continuous deep sedation until death for patients dying at home: A descriptive
15 study from Belgium. *Eur J Gen Pract* 2011;17:5-13.
- 16 (12) Rietjens JAC, van der Heide A, Vrakking AM, et al. Physician reports of terminal
17 sedation without hydration or nutrition for patients nearing death in the Netherlands. *Ann*
18 *Intern Med* 2004;141:178-85.

1 (13) Anquinet L, Rietjens JAC, Seale C, et al. The practice of continuous deep sedation until
2 death in Belgium, the Netherlands and the United Kingdom: A comparative study. J Pain
3 Symptom Manage. In press 2011.

4
5
6

7

8

9

10 **TABLES**

11 *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§	0	0
Setting				
Oncology ward	1	0	0	2
Palliative care unit	2	2	3	3
Home*	1	2	1	4
Experience with continuous sedation				
Yes	2	4	4	9
In the last year†	3	3-4‡	1-4	1-30
In the professional career†	5‡	2-50‡	10-15‡	3-15‡
No	2	0	0	0

1 * In the home care settings, physicians included general practitioners, whether or not part of a palliative home care team. Nurses in the

2 home care setting were always member of a palliative home care team.

3 †The number of times physicians or nurses have had experience with continuous sedation until death.

4 ‡Missing: Focus group 1 Physicians (*In the professional career: n=1*); Focus group 2 Physicians (*In the last year: n=1; In the*

- 1 *professional career: n=1*); Focus group 1 Nurses (*In the professional career: n=2*); Focus group 2 Nurses (*In the professional career:*
- 2 *n=3*)
- 3 §85 years, retired.
- 4 || 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:*
- 5 *n=1*)
- 6
- 7
- 8
- 9

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

Introduction

Part I: Types of sedation

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

Part II: Understandings of and experiences with of 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 in which patients are continuously sedated until death?

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? †

Closing; answering questions; thanking the participants

1 *The questions for nurses were: “In which types of sedation for patients in their last phase of life
2 have you been involved? How would you define these? How have you been involved in the
3 performance of continuous sedation for a patient in her last phase of life?”

4 †The question for nurses was: “Are there situations in which your involvement in the
5 performance of continuous sedation until death is more easy or more difficult for you?”

6

7

8

9

10

11

12

13

14

15

16

17

18

1 **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 to relieve 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 can't 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 any more. **Midazolam is administered to bring the patient into a deep sleep. The patient no longer reacts any more 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 to 4 weeks. The**

patient dies 1 week after the start of Midazolam.

1

2

3

4

5

6

7

8

9

10

11

12

13