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# Using continuous sedation until death for cancer patients: A qualitative interview study of physicians' and nurses' practice in three European countries

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## Abstract

**Background:** Extensive debate surrounds the practice of continuous sedation until death to control refractory symptoms in terminal cancer care. We examined reported practice of United Kingdom, Belgian and Dutch physicians and nurses.
**Methods:** Qualitative case studies using interviews.
**Setting:** Hospitals, the domestic home and hospices or palliative care units.
**Participants:** In all, 57 Physicians and 73 nurses involved in the care of 84 cancer patients.
**Results:** UK respondents reported a continuum of practice from the provision of low doses of sedatives to control terminal restlessness to rarely encountered deep sedation. In contrast, Belgian respondents predominantly described the use of deep sedation, emphasizing the importance of responding to the patient's request. Dutch respondents emphasized making an official medical decision informed by the patient's wish and establishing that a refractory symptom was present. Respondents employed rationales that showed different stances towards four key issues: the preservation of consciousness, concerns about the potential hastening of death, whether they perceived continuous sedation until death as an 'alternative' to euthanasia and whether they sought to follow guidelines or frameworks for practice.
**Conclusion:** This qualitative analysis suggests that there is systematic variation in end-of-life care sedation practice and its conceptualization in the United Kingdom, Belgium and the Netherlands.

## Keywords

Refractory symptoms, continuous sedation until death, qualitative research, palliative care, palliative sedation, end-of-life care

**What is already known about this topic?**

- Extensive clinical and ethical debate surrounds the practice of sedation for symptom palliation in end-of-life care, but is rarely informed by experiential accounts from clinicians who care for dying people.
- Existing research, mainly survey based, shows that clinical practice with sedation in end-of-life care varies by country in spite of clear guidelines; the reasons for this are not understood.

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**What does this paper add?**

- Continuous sedation at the end of life is practised and perceived differently by physicians and nurses in the United Kingdom, the Netherlands and Belgium.
- Differences in practice can be explained by the different values and concerns that UK, Belgian and Dutch clinicians have with regard to consciousness during dying, hastening death, continuous sedation as an 'alternative' to euthanasia and using guidelines for practice.

**Implications for practice, theory or policy**

- Our findings point to the need for greater understanding of different cultural and ethical perspectives on appropriate courses of action for the relief of suffering in the variety of challenging situations that clinicians are likely to face at the bedside.
- Ethical dilemmas associated with sedation in end-of-life care can be usefully illuminated by carefully designed empirical studies enabling international comparisons.

## Introduction

Extensive debate surrounds the practice of palliative sedation,[1] which entails the deliberate lowering of consciousness of a patient. Palliative sedation can be given in two ways: (1) short-term or intermittent sedation or (2) continuous sedation until death.[2] Guidelines or frameworks for European practice recommend that the use of continuous sedation until death for refractory symptoms giving rise to unbearable suffering should occur only when the patient's disease is irreversible and advanced and that there should be no primary intent to hasten death.[2–4] However, empirical studies suggest that the practice varies across a number of dimensions, including prognosis, whether suffering is perceived as physical or existential,[5] types of drugs used,[6] depth[7] and whether the patient has decisional capacity or has requested assisted dying.[8] Physicians' religious or ethical perspectives are associated with different practices.[9–12] Existing evidence also suggests differences by country. A comparative secondary analysis of questionnaires sent to physicians in Belgium, the Netherlands and the United Kingdom[13] found that 'country' predicted the probability of reporting use of 'continuous deep sedation', even when correcting for other variables. A qualitative study in the United States and the Netherlands showed that justifications for sedation differed.[14] Furthermore, a small qualitative study[15] found that Dutch and Belgian interviewees positioned continuous sedation until death as an 'alternative' to euthanasia, while UK interviewees placed emphasis on the medical management of symptoms. In 2005, the Royal Dutch Medical Association published a guideline.[16] A comparable guideline was published in 2012 in Flanders, the Dutch-speaking region of Belgium.[17] No national guideline exists in the United Kingdom.

In this article, we report results from the UNBIASED study (UK–Netherlands–Belgium International Sedation Study)[18] to compare how physicians and nurses from these countries describe their practice and what rationales they use.

## Participants and methods

Details of the methods employed are available elsewhere;[18] we provide a summary here. The study was approved by research ethics committees as follows:

United Kingdom: Leicestershire, Northampton and Rutland Research Ethics Committee 1, 10/H0406/57
Belgium: Ghent University Hospital Ethics Committee, B670201010174
Netherlands: Erasmus MC Medical Ethical Research Committee, NL33327.078.10, v03

Each participant gave written informed consent before taking part. We followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines in reporting this study.[19] Data collection took place between January 2011 and May 2012.

### *Study design*

A qualitative case study design enabled exploration of a complex phenomenon from a variety of perspectives.[20] Each case comprised the physician, nurse and bereaved relative of an adult cancer patient who had received continuous sedation prior to death.

### *Settings*

To enable maximum variation in the cases studied,[21] we conducted the study in hospitals, the domestic home and hospices (United Kingdom and the Netherlands) or palliative care units attached to hospitals (Belgium).

### *Participants and inclusion criteria for decedents*

Nurses and physicians were invited to take part if they had been closely involved in the care of patients aged over the age of 18 years who had died of cancer and to whom

**Table 1.** Physicians' and nurses' characteristics.

| Characteristics | Physicians (n = 57) | | | Nurses (n = 73) | | |
|---|---|---|---|---|---|---|
| Country | UK (n = 17) | BE (n = 18) | NL (n = 22) | UK (n = 25) | BE (n = 20) | NL (n = 28) |
| Age (years) | | | | | | |
| <40 | 7 | 5 | 10 | 9 | 7 | 12 |
| 40–50 | 6 | 6 | 3 | 8 | 7 | 7 |
| >50 | 4 | 6 | 9 | 5 | 5 | 9 |
| Not stated | 0 | 1 | 0 | 3 | 1 | 0 |
| Gender | | | | | | |
| Male | 8 | 9 | 12 | 0 | 3 | 2 |
| Female | 9 | 9 | 10 | 25 | 17 | 25 |
| Specialism | | | | | | |
| Primary care | 5 | 7 | 10 | 3 | 6 | 1 |
| Palliative home care team | 0 | 2 | 0 | 4 | 5 | 8 |
| Hospital oncology ward* | 4 | 2 | 3 | 2 | 5 | 9 |
| Palliative care unit/ hospice care | 8 | 7 | 9 | 16 | 4 | 10 |

UK: United Kingdom; BE: Belgium; NL: The Netherlands.

sedating medications with the intention to decrease awareness were administered continuously to alleviate otherwise uncontrollable symptoms (either physical or psychological/existential), and for whom the sedation was in place at the time of death. Senior clinical staff identified eligible decedents and then nominated the physicians and nurses most involved in their care. Physicians and nurses were interviewed about no more than three patients. Interviews took place as soon as possible after death. In most cases, this was within 2 months.

### *Procedures*

Interviews were semi-structured using an *aide mémoire*.[18] Interviews focused on recollections of the care of the decedent, reasons for the use of sedation, its implementation and decision-making. Interviews were audio recorded, transcribed and translated as required. Recruitment to interviews commenced in January 2011 and was complete by May 2012.

### *Analysis*

We wrote up the interviews attached to each decedent's case into qualitative case studies. To aid rigour, for selected cases, this was done independently by two researchers from different countries,[22] with cross-case comparison undertaken by exchange and study of different cases from different countries and care settings by the international research team. In addition, we undertook a thematic analysis based on Strauss and Corbin's constant comparative method[23] to aid within-case analysis. We presented overviews of findings to clinical audiences, including some study participants, in a process of respondent validation.[22]

## Findings

We studied 84 patient cases (22 UK; 35 NL; 27 BE) involving interviews with 57 physicians (17 UK; 22 NL; 18 BE) and 73 nurses (25 UK; 28 NL; 20 BE). Table 1 gives characteristics of the interviewees, showing that the majority (73 out of 130) were palliative or hospice care practitioners. Table 2 provides an overview of the characteristics of the patients and their care setting. Table 3 provides examples of the range of reasons described by participants for provision of continuous sedation until death. Some details have been omitted from the tables and subsequent presentation of quotes to ensure concealment of patients' identities. Some clinical information has been given where we judged that this would help readers understand the context of the quotes.

### *United Kingdom*

*The practice of continuous sedation until death as reported by UK physicians and nurses.* UK respondents described a continuum of practice, from the provision of low doses of sedatives commonly given to patients to control terminal agitation or restlessness (referred to as 'normal end of life care with sedation' by one hospice physician) to the provision of continuous deep sedation in rare and highly memorable situations where it was exceptionally challenging to bring suffering under control:

> I think the Liverpool Care Pathway has been extremely helpful in highlighting that agitation at the end of life is relatively common and can be well treated and well managed, and the quality of end of life care that patients receive and families experience can be improved by recognising that as a symptom and treating it. And I would put that into the bracket

**Table 2.** Characteristics of patients.

| Cases (Belgium (n = 27), Netherlands (n = 35), United Kingdom (n = 22)) | n = 84 |
|---|---|
| Age (years) | |
| <40 | 6 |
| 41–60 | 20 |
| 61–80 | 45 |
| >80 | 11 |
| Unknown | 2 |
| Gender | |
| Male | 43 |
| Female | 41 |
| Diagnosis | |
| Adenocarcinoma, peritoneal or sarcoma | 5 |
| Abdominal/stomach | 3 |
| Bladder/renal | 7 |
| Colo-rectal | 8 |
| Brain/glioblastoma | 6 |
| Breast | 5 |
| Gynaecological | 4 |
| Oesophageal | 1 |
| Gall bladder/pancreatic | 7 |
| Leukaemia/myelofibrosis/ myeloma | 4 |
| Lung/mesothelioma | 16 |
| Melanoma | 4 |
| Prostate | 7 |
| Unknown primary | 7 |
| Care setting | |
| Home | 30 (9 UK; 11 BE; 10 NL) |
| Hospital | 28 (4 UK; 10 BE; 14 NL) |
| Palliative care unit (BE)/ hospice (UK/NL) | 26 (9UK; 6 BE; 11 NL) |

> of, of relatively normal end of life care with, with sedation. There are some cases – and they, they stick in your mind and you'll probably get a few of them in the study – where, you know, it taxes people enormously … to make sure that somebody isn't distressed or agitated at the end of life. (Consultant physician, hospice 2, case 4)

> So in the end we gave him some phenobarbitone and he needed three injections of 200 mg before he finally settled, but he died a few hours later. So we did settle him in the end, but it was unpleasant for everybody, and his wife had a very difficult time. I think she found it very hard, understandably … he had very resistant agitation is what I'd say. So phenobarbitone's not something we use very frequently and it's something we use so infrequently that you think, 'Oh my goodness, how do we use it?' (Consultant physician, hospice 1, case 7, reflecting on the care of a man who died of lung cancer and suffered extreme pain and distress)

Often, there was no intent reported for continuous sedation, once started, to continue until death. UK respondents, especially nurses, described using sedatives to ensure that dying patients were 'settled' or 'comfortable:

> … our aim when we set out to start a syringe driver and make the changes to the syringe driver, was to see if we can get her settled. (Specialist registrar, hospice 2, case 1)

> I don't usually use the word 'sedation', I use the term 'make him more comfortable and settled'. (Junior nurse, hospital case 3)

Being 'settled' or 'comfortable' was portrayed as being 'just rouseable', akin to light sleep. Several physicians described sedation as a 'side effect' of managing difficult physical symptoms:

> Actually what we're aiming for is the kind of minimum amount of sedation needed to get symptoms under control … it may require regular medication along with extra doses and needing sort of quite, quite heavy doses of sedation, but, you know, the aim isn't to sedate the aim is to relieve symptoms … we try very hard to give the medication for the symptom relief with a recognised side-effect that we're trying to minimize. (Consultant physician, hospice 2, case 2, reflecting on the care of a man who died from metastatic cancer, with terminal agitation)

An example of this was when one junior doctor said that she did not give people continuous sedation but instead '*medications to relieve agitation'*, which had sedative side effects:

> I haven't given anybody continuous sedation; there have been lots of patients who have become agitated at the end of their lives and in those cases it's appropriate to give medications to relieve that agitation and that restlessness, so we are giving drugs that do have sedative effects but the aim is not necessarily to sedate, the aim is to relieve that agitation and restlessness and make them more comfortable. (Junior doctor, hospice 1, case 4)

In the United Kingdom, normal practice was reported as entailing provision, usually at the nurse's discretion, of low doses of 'core' sedative, anti-emetic and analgesic drugs to the patient in accordance with a prescription that had been written up by physicians in anticipation of symptoms which may occur. In the cases studied, there were no reports on the provision of clinically assisted hydration once continuous sedation was started, except for the delivery of medication:

> We tend to give small doses; 'prn' to begin with, and then perhaps another one or two if that is not successful. But then we would move to a syringe driver, rather than going in and giving 5, 6, or 7 'prn' doses a day. We can't do that so we tend then to go to syringe driver, it makes it easier to manage a case. (Nurse, community, case 1)

> I think this patient was only in [hospice] for, for less than two days – we always start with quite low doses; we always start

**Table 3.** Example of the range of reasons for using continuous sedation until death.

| |
|---|
| *Refractory pain and/or delirium* |
| '… at night, with the change in how he coped, his character changed completely. He became aggressive; he became abusive and was not a man you could reason with, and we felt as though, as a team, we were chucking the cupboard at him and nothing was touching this pain. And we went through escalating doses of … well, the ketamine, we added in clonazepam, we added in other opiates, and we just didn't seem to be getting anywhere. And this behaviour of non-coping and escalated pain then began to encroach into the day as well … And even that, with the doses of phenobarbitone that was the case, you know, it wasn't a quick, easy solution'. (UK hospice nurse, case 7, reflecting on the care of a man who died of lung cancer, with extreme pain and distress) |
| 'It [sedation] was discussed with the family and [patient] because of the pain … Because the handling was extremely painful'. (Belgian general practitioner, case 1, reflecting on the care of woman with cancer and a hip fracture, who died at home and suffered extreme pain from her hip fracture) |
| '… she indeed became increasingly confused, painful, without the actual possibility of adequate medical therapy anymore'. (Netherlands, hospital physician, case 1, reflecting on the care of a woman with refractory pain and generalized extreme distress) |
| '… there was a lot of confusion, a lot of agitation and the doctor who was looking after him sort of ran to the bay with the nurses and tried to calm him down. He was very aggressively agitated'. (UK junior hospital doctor, case 3, reflecting on the care of an elderly man who died in hospital with cerebral metastases) |
| *Responding to a patient's request for relief from pain* |
| '… And I discussed that, yes, that was an option for her to be put to sleep [to] make you feel comfortable [so] that she would not feel the pain'. (Belgian oncologist, case 17, reflecting on the care of an elderly woman with pancreatic cancer, who died in hospital) |
| *Refractory nausea and vomiting* |
| '… the medicines he was having to control his sickness, it wasn't controlling it. It was, it was breaking through. I'd say after three, maybe four days, it was starting to present itself and it was pretty bad'. (UK general practitioner, case 1, reflecting on the care of an elderly man who died at home with gallbladder cancer) |
| '… Thursday night he started vomiting blood, and he was, at that moment he was conscious and approachable and vomiting blood and we had to give extra [sedative] medication against the vomiting' (Belgian general practitioner, case 9, reflecting on the care of a man who died at home with metastatic cancer) |
| *Refractory dyspnoea* |
| '… on Monday morning he was still there, but, he was very miserable so I then decided; I going to sedate him because it wasn't really possible anymore'. |
| I: *And how do you mean miserable?* |
| 'Miserable, he was gasping like a fish out of water even with maximum oxygen, soaked in sweat and stressed … Terrified, couldn't get comfortable and could barely talk'. (Netherlands oncologist, case 12, reflecting on the care of a young man with metastatic cancer who died in hospital) |
| '… A combination of dyspnoea, pain, confusion and clear clinical deterioration for which you have exhausted all possibilities to fix it with medication'. (Netherlands, hospital physician, case 2, reflecting on the care of a man who died of sarcoma) |
| *Existential suffering* |
| 'The man was above all, actually had a lot of existential problems. That was someone who belonged on the palliative unit but at that time there was no place there. That man actually asked to be left alone and [for] peace in the last days of his life …' (Belgian oncologist, case 18, reflecting on the care of elderly man who died in hospital) |

> in a cautious way and sometimes when you do that, people need another dose and then another dose and then an escalation in the dose in their syringe driver, because you've started cautiously and built up rather than starting with a high dose and then, and completely flattening somebody at the outset, and that can sometimes be difficult. I think it's, these sorts of cases are ones where the patient needs regular review and the family need to know that that's the intention, to review regularly and to be able to give an extra dose if necessary. (Consultant physician, hospice 2, case 4, reflecting on the care of a woman who died from glioblastoma, which he said typified normal practice with sedation)

*Reported rationales for practice.* Four factors provided a rationale for the practice as reported by UK practitioners. First, many UK respondents were anxious that the use of 'heavy' doses of sedative may hasten death or be seen to be equivalent to euthanasia. This was notably present among nurses, and less so among hospice consultants. Dilemmas were perceived to be posed by patients who requested assisted dying; hospice respondents reported that this sometimes occurred in patients with very high symptom burdens:

> So I know our tendency is to start small because people worry about it and they worry that people will suddenly be sedated and people will assume that's what's killing them … And even in hindsight thinking, 'Would I have done it differently?', talking to my team they all said, 'But [nurse's name] we always start small'. (Specialist palliative care nurse, hospital, case 1, reflecting on difficult death of a man from lung cancer, with uncontrolled symptoms)

Second, UK physicians and nurses sought to ensure that patients could maintain interaction for as long as possible, while seeking to provide enough sedation to ensure that

patients became 'settled' and 'comfortable'. Some respondents considered it to be morally wrong to decrease or remove a patient's consciousness:

> He was needing to have quite a lot of extra doses in that last period, and there's, there is a sense that you don't want to over-sedate people … looking back at that … I think I might have put a bit more in the driver considering he was already on quite a lot of oral or, you know, peg diazepam. But I think staff have a real concern they don't over-sedate people because they don't want to be seen to be knocking them out. I guess when you're looking at how much you sedate people, it's important to be proportionate; it's also important to be effective. (Consultant physician, hospice 1, case 3, reflecting on the care of a man who died with difficult symptoms and who requested sedation)

> … we're probably a little bit more cautious in general practice in terms of how we, how we start it. And, and that might be to the detriment of the patient at times, I wonder. (General physician, community, case 3)

> … we want them to be comfortable but we don't want to totally knock them out and not have interaction with their family; and the family is quite happy to see him comfy, settled. (Junior nurse, hospital, case 3)

Third, commencement of the Liverpool Care Pathway was reported to be a signal to activate an anticipatory prescription (sometimes referred to as 'just in case' prescriptions), including the use of sedative drugs:

> … when we start the Liverpool Care Pathway at the end of life – the end of life drugs that are prescribed anyway in case all these symptoms associated with dying come up – and if we feel, like the nurses feel that my patient is getting agitated or is in a lot of pain, we can just go ahead and give it. And they always prescribe like a range starting from the lower to the upper limit so we just sort of titrate and go up as, you know, how much your patient needs or how agitated they're getting. (Nurse, hospice 1, case 4)

Fourth, respondents were concerned to ensure that they balanced the perspectives of patients, families and their colleagues when deciding how to manage a patient's distress. This was especially noticeable in the 5 out of 22 cases studied where patients had what one respondent described as 'resistant agitation' (see Table 3):

> How do you do something to a patient, even if it's what we want, that the family are saying you mustn't do? And the books say: competent patient, ignore the family, do what the competent patient wants … I mean the books would say he was competent and we were all clear, the psychiatrist was clear, he wasn't depressed, he was competent, he wanted to be asleep, we'd tried everything else … but how do you sedate someone fully when the wife is saying, 'Don't do it'. I don't know. (Consultant physician, hospice 1, case 1, reflecting on the care of a man whose wife was unhappy about the use of sedation)

> I go and say [to the family], 'It's **we** who made the decision, and not **I** who made the decision', so, and that gives more strength saying it's me as a part of the team'.(Specialist registrar, hospice 2, case 1)

> I would still always ring the out-of-hours GPs even though it's [drugs are] written up, and discuss it and you'll find that the out-of-hours doctors are, you know, some will either come out or discuss it over the telephone with you and be happy to, to go on your clinical judgement. But, yeah, I think it's got to be a team decision'. (GP, community case 8)

## *Belgium*

*The practice of continuous sedation until death as reported by Belgian physicians and nurses.* In Belgium, there was a variety of patterns in respondents' accounts. The predominant pattern was to seek to relieve patients' suffering by establishing deep sedation either by starting with low doses of sedatives and then increasing these quickly, or by the provision of high dosages from the outset:

> The aim of sedation is really to get someone fully sedated. As I said, we had a discussion about this on a daily basis with the palliative team and then it was switching to barbiturates, which was something we would have done, well, if I had estimated that it would still have taken a few days, we would certainly have done that … In retrospect you could say, maybe we should have switched from Dormicum [midazalom] to other products a day earlier. (GP, community case 9, reflecting on the care of a man who died with metastatic cancer)

> I know in the beginning, uh, the first day she wasn't really asleep. Then I did get back in contact with [Palliative Home Care Nurse Association] and then the medication was increased … normally speaking they enter a deep sleep fairly quickly they, but that actually wasn't the case with her, although she wasn't in pain

> I: So first it was too low and then it was increased?

> And then she was actually in a deep sleep, yes. (Nurse, community case 4)

> We used the Pentothal to deepen the sleep of the man and he died the next day at 21.00 o'clock … we never give fluids or nutrition … we always stop in time, preferably before we start with the sedation, but at the time of sedation. Then we basically stop everything, because you want to support a natural dying process, or initiate it as was done here. (Physician, palliative care unit, case 5, describing continuous deep sedation over 8 days, with an anaesthetic agent used on day 7, in the management of a man who was reported to have lost the will to live)

In the few examples where it was reported that patients had lost capacity, no such attempt to induce deep sedation was described. Instead, sedation was described as 'medical decision'; for example, in one case, a general physician (GP) described it as an 'acute medical help' for refractory dyspnoea in his recollections of caring for a patient with lung cancer:

> [We] eventually administered sedating medications and then they started at a dose which offered relative certainty that she would be calm. … So in fact there we did not have a deep sedation; there was no request from her and there wasn't really a request from the family … it was decided to proceed to sedation, but rather in relation to the symptom. (Physician, palliative care unit, case 6, reflecting on the care of a woman who died from a glioblastoma)

> And at that moment I thought yes, this guy is too scared now to rationally decide for himself and I need to intervene. So I took the family outside to discuss the matter with them, they had been sitting with him for the past 72 hours with a scared look on their faces and I said 'look I will intervene for his own good and put him to sleep because he is too afraid to say yes now' … the family agreed and was also glad that I had suggested it. … So I started with the dose he needed at [the previous night]. I always start with a dose of one mg per hour and every hour I get the nurses to evaluate how it's going and increase it, for me. When they are sleeping peacefully, then they freeze the dose. (Oncologist, hospital oncology unit, case 12, reflecting on the care of a young man with refractory dyspnoea)

It was reported to be usual practice to withdraw or withhold clinically assisted nutrition and/or hydration as soon as continuous sedation until death started, unless a patient had made a specific request to receive hydration. Belgian nurses reported a variety of responsibilities with regard to their role, from the provision of advice to GPs, to carrying out physicians' instructions. Belgian respondents made a variety of references to guidelines and protocols: some relied on experience; others reported consultation with local palliative care specialists. A few made reference to Dutch guidelines:

> I don't know if they have something like that in the department here, or if an actual protocol was written, but I've always – I have my own standards. (Oncologist, hospital oncology unit, case 16)

> No, only a consultation with the palliative network. (GP, community, case 1)

> We must follow the instructions of the doctor … because we always depend on the doctors to start the treatments. (Nurse, community, case 1)

> No. I have taken a course in palliative care, but no guidelines were ever mentioned. (GP, community, case 2)

> I have the protocol … that is the protocol from the Netherlands … yes I also used these guidelines with this case. This is also in my doctor's bag – the guidelines from the KNMG. (GP, community, case 25)

*Reported rationales for practice.* Three factors could be identified that provide a rationale for the practice reported by Belgian practitioners. First, most wanted to prevent patients coming to consciousness once sedation had been started and sought to sustain 'deep sleep' until death:

> In principle it is the intention, if we sedate, that they really are well asleep because it is often confusing for the family that waking and sleeping, often … the family no longer expects that either and often when they are awake, they are still a bit restless and … 'Gosh am I still here and …' So I don't find that necessary. Palliative sedation, I do prefer that they really are fully sedated. (Oncologist, hospital oncology unit, case 18)

Second and closely linked to the first was the perceived importance of honouring patients' requests to be 'taken out of suffering' or to be 'put to sleep':

> I just clearly said 'look I am willing to do that if you want, we've talked about it, we've discussed it with you … it is you who decides. (GP, community, case 4)

> He then came to the unit and said 'I want to die like my wife'. So, for him it was rather more of an existential question really. He wanted to die as his wife had. The symptoms that were bothering him or encouraged him to determine the time or moment was due to being bedridden, having decreased mobility and pain, the man had many symptoms such as chest pain caused by the illness that he had. It was also his fear of pain that actually helped him decide, despite the fact that it felt like we had his pain quite well under control. However, it was mainly the fear.
>
> I: So, the fear of future pain?
>
> The fear of future pain, especially the fear of future pain, the decay process and the 'being done'. (Physician, palliative care unit, case 5)

Third, a predominant emphasis (in 18 of 25 cases) was the description of continuous sedation until death and euthanasia as 'alternatives' with discussions with patients and their families reported about these 'options'. In five cases, physicians reported using continuous sedation until death for patients who had requested euthanasia but then become incompetent before they were either able to complete the formal process or discuss their wish with their family. In the other cases studied, continuous sedation was preferred by the physician over the possible 'choice' of euthanasia for moral reasons, or because patients preferred continuous sedation. Respondents accepted that continuous sedation until death may hasten death where it extended

over several days, although most said this was not their primary intention. In two cases, palliative care unit physicians described an explicit life-shortening intent:

> … we have had, yes, a very open conversation once she indicated that she wanted to put an end to it. So we listed the various options available so ranging from – from actually waiting until it being spontaneous, to euthanasia – and, as an alternative, palliative sedation. (Oncologist, hospital oncology unit, case 20)

> I should have had the conversation about euthanasia in the beginning, because that was perhaps a better option [but] there is a group where perhaps palliative sedation is a more appropriate option because euthanasia is out of the question for them. So I see them as complementary. (GP, community, case 25)

> It's not a coincidence that eventually euthanasia is being done a lot less frequently than sedation, because somehow … sedation is considered to be more naturally and it's also more in line with what the natural process brings: more sleep. (Physician, palliative care unit, case 26)

> With the intention of, with sedation, but not to take too long. From a … to have a shortening effect. I'm honest about that. I think that is okay, given the euthanasia desire, so, yes, it's, yes, I would rather say a sedation but surely in the direction of a slow euthanasia. (Oncologist, hospital oncology unit, case 23)

## *The Netherlands*

*The practice of continuous sedation until death as reported by Dutch physicians and nurses.* Dutch physicians and nurses typically reported using sedation where a refractory symptom was present and a patient was in the last days of life. They talked about making a 'formal' medical decision following discussion with the patient and/or their family and with colleagues:

> … then in the course of the morning, there were talks and in the afternoon we officially started with sedation … Well, the doctor explained to them [family] the details of how it works and what it means, that there is no more contact possible with the patient. (Hospital nurse, case 1)

> [The doctor] was just like: first I'm going to give that shot of Dormicum [midazalom], then we will immediately check the protocol and then I'll connect the pump. So I think that's how it happened … And yes that's a whole protocol of how you are going to start, with what dosage you give the first shot and how you proceed with the sedation … Yes, that all happened very officially. (Hospital nurse, case 8)

Usual practice was described as involving starting with low doses of sedative and then cautiously increasing the dosage until the patient was in a quiet and peaceful state. Once sedation was started, artificial hydration was usually reported to be withdrawn or withheld. In most cases, nurses described having responsibility for carrying out the doctor's instructions, monitoring the response of the patient to the sedatives once started and, if required, increasing the dosages according to medical instruction:

> Yes, if people, if the family, or us, nurses or doctors feel that the patient is still a bit restless, then the dosage is increased … But thus far, from what I've experienced a large increase is rarely needed. (Hospital physician, case 1)

> So look, you're trying to get the situation under control again, you try to create peace and it's not about injecting someone out of this world, you just want the situation to be calm again. For the patient, for the relatives. But you do not want too much. (Hospital nurse, case 4, reporting on the care of a patient with cerebral metastases)

> With the dose that we give we always try to start with the lowest dose, so we don't force anything … we just start according to the guideline, low. (Hospice physician, case 21)

*Reported rationales for practice.* In the Netherlands, the presence of the national palliative sedation guideline framed most respondents' reports. For example, the manner of titration of medications was described to be prescribed by the guideline. Terms related to key indications for continuous sedation in the guidelines were used frequently by the respondents, such as 'refractory suffering'. However, several Dutch physicians reported that they found it sometimes necessary to 'work round' the guideline to meet patients' needs, especially when suffering was perceived to be neither wholly physical nor refractory:

> … we have a protocol for sedation, which is of course approved through the KNMG [Koninklijke Maatschappij ter bevordering van de Geneeskunde – Royal Dutch Medical Association], which is used nationwide. (Hospital nurse, case 4)

> Yes you must do this according to the protocol. Of course you need to have good communication with family, doctors and nurses and be on the same wavelength. (Hospital nurse, case 8)

> We definitely follow the rules when it comes to sedation. So the prognosis has to be less than two weeks, with refractory symptoms. And sometimes I think that we have to wait too long for that … So when she got the itch that we could do nothing about I thought hooray, we have a refractory symptom, now we can do sedation … (Hospital physician, case 3, reflecting on the care of a woman with renal cancer)

Second, while some Dutch respondents talked about continuous sedation and euthanasia as 'alternatives', others made a clear distinction. It was explained that contrary to euthanasia: that first, sedation is a natural death, neither directly contributing to death nor hastening it:

> So it's basically just nature doing her job. So in that respect it's not actively contributing to death. Only in the way that everything else stops completely, the intake of fluids … Of course that can indirectly hasten death, but it is not an active termination … [in] euthanasia we often indicate that it has to be a longer process and that someone has to indeed be completely lucid … [the options discussed were] euthanasia, sedation or the natural way. Well, sedation is the natural way with a lot of symptom control. (Hospital physician, case 2, reflecting on the care of man who died of sarcoma)

Second, it was explained that sedation controls refractory symptoms when the requirements for euthanasia cannot be met (such as lack of capacity or too little time to consult a second physician), and third, it was explained that the use of sedation is primarily a medical decision:

> Yes, the psychiatrist, the ward doctor, and then yes the nurse who cared for her. And well yes, Mrs. X and her husband were probably also involved in the decision … it is in principle a decision that the doctor in consultation with the patient … and then the nurse … And the ward doctor consults [about] that with the supervisor. (Hospital nurse, case 3)

> Quote 11: That first discussion was the most important, it took place on [date]; at that time we considered the options. Choices were made then. I am a general practitioner who prefers to work with palliative sedation. I do have some difficulty with euthanasia.
>
> I: And what did he think of this? Did you also discuss euthanasia at this time?
> R: Yes of course we discussed it.
> I: And what did he think of this?
> R: Initially, he thought that euthanasia would be a good solution. But when I explained the method of palliative sedation to him, he said he would like to have this too. Then the decision is not difficult for me to make. So finally, after a really thorough discussion we decided on palliative sedation. And that's the way it goes. I admit that my guidance played some part in the decision … The decision is mine, and I wish to emphasize this fact to people – this is another thing that goes with palliative sedation. I have said that the decision is mine to make because palliative sedation cannot be administered in every situation. (GP, Case 11: reflecting on the care of man who died of lung cancer).

Some interviewees welcomed a quick death once sedation had been started and a minority pattern of perception was that sedation does hasten death:

> Yes, what you do read and hear is that people do not die sooner because of palliative sedation; I don't believe any of it. That doesn't correspond with my practical experience; it almost always goes incredibly fast. (GP, case 12)

> … it increases the process of death … so I definitely think that it plays a role. (GP, case 15)

The third rationalizing factor was the need to ensure that once sedation was commenced, the patient did not come to awareness so that suffering was avoided:

> Yes, deep sedation, really a dormant state, a body which is at rest and so is a little relaxed. And the moment that you are going to turn them, that there is no response. (Hospital nurse, case 4)

> And so of course it had to be done well, because I could not have it that she would still wake up or that something else would happen and that I was not there. Then the pump would immediately need to go up, because she had to remain comfortable. (Hospital physician, case 10)

## Discussion

This exploratory study of the use of continuous sedation until death for cancer patients has shown that UK respondents report a continuum of practice from the provision of low doses of sedatives to control terminal restlessness to rarely used continuous deep sedation. In contrast, Belgian respondents predominantly describe the use of deep sedation, emphasizing the importance of responding to the patient's request for relief of suffering. Dutch respondents place emphasis on the making of an official medical decision informed by the patient's wish where this is known and establishing that a refractory symptom was present before commencing sedation. Respondents employed rationales that showed different stances and values towards four key issues in the three countries. The first issue involved the preservation of consciousness. UK respondents sought to maintain patients in a 'settled' but 'just rouseable' state. This gave raise to their descriptions of sedation as a 'side effect'. In contrast, Belgian practitioners reported the need to ensure that patients 'stayed asleep', focusing on honouring the choice of a patient who asked for sedation. A more mixed picture with regard to consciousness was observed in the Dutch accounts, although most set a similar value on 'staying asleep'. There has been comparatively little attention to the values placed on consciousness in previous research, although quantitative studies reveal contradictory stances both within physician samples and between countries.[9] Our findings resonate with the results of a Japanese survey, which found that continuous sedation was more frequently performed by physicians who did not believe consciousness was necessary for a good death.[24] A qualitative study of Dutch physicians showed that depth of sedation varied according to whether physicians placed emphasis on the duty to relieve suffering or the duty to observe the patient's response to medication.[7] Our finding that UK physicians referred to sedation as a 'side effect' resonates with results from a survey of US physicians where 85% agreed that

unconsciousness is an acceptable side effect of palliative sedation mirroring language in US guidelines.[25]

The second key difference concerned perspectives towards hastening death. Although there is a body of evidence showing that where sedation is performed correctly, it does not hasten death,[26] interviewees took variable positions towards this. UK practitioners thought hastening death may be a possible result of the use of continuous sedation and wanted to avoid this; findings that are similar to those from a study of Australian palliative care specialists.[27] In contrast, some Belgian physicians accepted that continuous sedation may hasten death and in two cases reported a life-shortening intent. In the Netherlands, most practitioners did not perceive that sedation hastened death, and they tended to describe continuous sedation as enabling a 'natural' death.[28]

A third difference centred on whether continuous sedation until death could be an alternative to euthanasia. There was little mention of euthanasia by UK respondents; clearly, this will have been influenced by the fact that there has been no legalization of euthanasia in the United Kingdom. In contrast, most Belgian respondents perceived continuous sedation until death and euthanasia to be 'alternatives' which could be chosen by patients. This perception appeared less strongly in the Dutch accounts; although Dutch clinicians sometimes reported discussing the 'option' of continuous sedation until death with patients, this was usually in situations where euthanasia had been talked about at an earlier point but could not be carried out at the time of the appearance of refractory suffering. While the European Association for Palliative Care has issued an ethical statement distinguishing between the two practices,[29] our data suggest that the perceptions of practitioners working in countries where euthanasia has been legalized suggests they take a different view; this needs further attention in future research.

Fourth, the degree to which reports of practice were shaped by the presence or absence of guidelines was notable. Dutch respondents referred very frequently to the 'official' recommendations in a national guideline which has legal ramifications, while reference to guidelines in the Belgian accounts was much more variable. Among UK respondents, especially those in non-hospice settings, the commencement of the Liverpool Care Pathway was regarded as a permissive 'signal' for use of low doses of 'core' drugs including sedatives where the patient started to exhibit signs of agitation. Previous Dutch research suggests that practice has changed towards compliance in the Netherlands since the publication of the national guideline, although there remains variety in symptom directed treatment and some concerns about life-shortening consequences of sedation.[30] Existing research in Belgium resonates with our findings, suggesting that Belgian physicians tend to be unfamiliar with existing recommendations and engage in variety of practices when using sedation in end-of-life care, including life-shortening intent, that are out of step with the latter.[31,32] There is no rigorous research about the relationship between the Liverpool Care Pathway and sedation practice, although audit data exist.[33]

### *Strengths and limitations*

The validity of this study was increased by purposively sampling physicians and nurses from three different care settings who had been closely involved in the end-of-life care of decedents identified using standardized criteria. However, this study has a number of limitations. Our interview data are dependent on the subjective experience and interpretation. Although our retrospective design does not preclude recall bias, this was limited in most of the cases by minimizing the time between the patient's death and the interview with the practitioners to 2 months. Further validation of our findings requires study of their resonance with other clinicians involved in the care of dying patients.

## Conclusion

Our findings point to the need for greater understanding of different cultural and ethical perspectives on appropriate courses of action for the relief of suffering in the variety of challenging situations that clinicians are likely to face at the bedside. Recognizing that practice is situated in different legal contexts, values and histories associated with palliative and end-of-life care may inform what are frequently contentious discussions about practice and policy in sedation.

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## References

1. Sterckx S, Raus K and Mortier F. *Continuous sedation at the end of life: ethical, clinical and legal perspectives*. Cambridge: Cambridge University Press, 2013.
2. Verkerk M, van Wijlick E, Legemaate J, et al. A national guideline for palliative sedation in the Netherlands. *J Pain Symptom Manage* 2007; 34(6): 666–670.
3. Cherny NI and Radbruch L; Board of the European Association for Palliative Care. European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care. *Palliat Med* 2009; 23(7): 581–593.
4. 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(1): 67–85.
5. Blondeau D, Roy L, Dumont S, et al. Physicians' and pharmacists' attitudes toward the use of sedation at the end of life: influence of prognosis and type of suffering. *J Palliat Care* 2005; 21(4): 238–245.
6. Reuzel RP, Hasselaar GJ, Vissers KC, et al. Inappropriateness of using opioids for end-stage palliative sedation: a Dutch study. *Palliat Med* 2008; 22(5): 641–646.
7. 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(7): E360–E366.
8. Claessens P, Menten J, Schotsmans P, et al. Palliative sedation: a review of the research literature. *J Pain Symptom Manage* 2008; 36(3): 310–333.
9. Cohen J, van Delden J, Mortier F, et al. Influence of physicians' life stances on attitudes to end-of-life decisions and actual end-of-life decision-making in six countries. *J Med Ethics* 2008; 34(4): 247–253.
10. Pomerantz SC, Bhatt H, Brodsky NL, et al. Physicians' practices related to the use of terminal sedation: moral and ethical concerns. *Palliat Support Care* 2004; 2(1): 15–21.
11. Curlin FA, Nwodim C, Vance JL, et al. To die, to sleep: US physicians' religious and other objections to physician-assisted suicide, terminal sedation, and withdrawal of life support. *Am J Hosp Palliat Care* 2008; 25(2): 112–120.
12. Seale C. Hastening death in end-of-life care: a survey of doctors. *Soc Sci Med* 2009; 69(11): 1659–1666.
13. Anquinet L, Rietjens JA, Seale C, et al. The practice of continuous deep sedation until death in Flanders (Belgium), the Netherlands, and the U.K.: a comparative study. *J Pain Symptom Manage* 2012; 44(1): 33–43.
14. Rietjens JA, Voorhees JR, van der Heide A, et al. Approaches to suffering at the end of life: the use of sedation in the USA and Netherlands. *J Med Ethics*. Epub ahead of print 14 September 2012. DOI: 10.1136/medethics-2012-100561.
15. Seymour JE, Janssens R and Broeckaert B. Relieving suffering at the end of life: practitioners' perspectives on palliative sedation from three European countries. *Soc Sci Med* 2007; 64(8): 1679–1691.
16. Committee on National Guideline for Palliative Sedation and Royal Dutch Medical Association. *National guideline for palliative sedation*. Utrecht: Royal Dutch Medical Association, 2009.
17. Broeckaert B, Mullie A, Gielen J, et al. *Palliatieve sedatie*. Richtlijn, Versie: 2.0. 2012, http://www.pallialine.be/accounts/129/docs/richtlijn_palliatieve_sedatie.pdf
18. 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.
19. Tong A, Sainsbury P and Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32 item checklist for interviews and focus groups. *Int J Qual Health Care* 2007; 19(6): 349–357.
20. Payne S, Field D, Rolls L, et al. Case study research methods in end-of-life care: reflections on three studies. *J Adv Nurs* 2007; 58(3): 236–245.
21. Sandelowski M. Sample size in qualitative research. *Res Nurs Health* 1995; 18(2): 179–183.
22. Malterud K. Qualitative research: standards, challenges, and guidelines. *Lancet* 2001; 358(9280): 483–488.
23. Boeije H. A purposeful approach to the constant comparative method in the analysis of qualitative interviews. *Qual Quant* 2002; 36(4): 391–409.
24. Morita T. Differences in physician-reported practice in palliative sedation therapy. *Support Care Cancer* 2004; 12(8): 584–592.
25. Putman MS, Yoon JD, Rasinski KA, et al. Intentional sedation to unconsciousness at the end of life: findings from a national physician survey. *J Pain Symptom Manage* 2012; 46(3): 326–334.
26. Sykes N and Thorns A. The use of opioids and sedatives at the end of life. *Lancet Oncol* 2003; 4(5): 312–318.
27. Douglas CD, Kerridge IH and Ankeny RA. Narratives of 'terminal sedation' and the importance of the intention-foresight

distinction in palliative care practice. *Bioethics* 2013; 27(1): 1–11.
28. Raus K, Sterckx S and Mortier F. Continuous deep sedation at the end of life and the 'natural death' hypothesis. *Bioethics* 2012; 26(6): 329–336.
29. Materstvedt LJ, Clark D, Ellershaw J, et al. Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force. *Palliat Med* 2003; 17(2): 97–101; discussion 102–79.
30. Hasselaar JGJ, Verhagen SC, Wolff AP, et al. Changed patterns in Dutch palliative sedation practices after the introduction of a national guideline. *Arch Intern Med* 2009; 169(5): 430–437.
31. Anquinet L, Rietjens JA, 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 Pract* 2011; 17(1): 5–13.
32. Chambaere K, Bilsen J, Cohen J, et al. Continuous deep sedation until death in Belgium: a nationwide survey. *Arch Intern Med* 2010; 170(5): 490–493.
33. Gambles M, McClinchey T, Latten R, et al. How is agitation and restlessness managed in the last 24 hours of life in patients whose care is supported by the Liverpool Care Pathway for the Dying Patient. *BMJ Support Palliat Care* 2011; 1(3): 39–43.