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Kasper Raus

Continuous sedation at the end of life

Practice, perspectives and ethical analyses

Proefschrift voorgelegd tot het behalen van de graad van
Doctor in de wijsbegeerte

2013

Because I could not stop for Death,
He kindly stopped for me;
The carriage held but just ourselves
And Immortality.

We slowly drove, He knew no haste,
And I had put away
My labor and my leisure too,
For his civility.

We passed the school, where Children strove
At wrestling in a ring;
We passed the fields of gazing grain,
We passed the setting sun

We paused before a house that seemed
A swelling of the ground;
The roof was scarcely visible,
The cornice but a mound.

Since then'tis Centuries; but each
Feels shorter than the day
I first surmised the horses' heads
Were toward eternity.

(Emily Dickinson 1890)

Republished in (1993) *The Collected Poems of Emily Dickinson.* New York: Barnes & Nobles, 194-5.

Preface and acknowledgements

Death has been – and still is – a topic of great mystery and much interest. Its cultural impact can hardly be overestimated and death plays a central role in many of the world's greatest poems and novels. For many, however, death is no gentle carriageman as in the poem by Emily Dickinson and dying is no distant mystery, but they instead form a near and terrifying reality. For those who are terminally ill, saying goodbye to this world in a way they deem dignified is of immense importance. Continuous sedation at the end of life may provide them with the means to achieve this end. Thinking about continuous sedation is therefore also thinking about those in great need.

For four years I delved into the topic of continuous sedation, a practice which currently raises great societal debate. I tried to contribute to the discussion by raising ethical issues where others saw none, and by stressing that continuous sedation is not as simple as it might sometimes seem. The deeper I got into the topic, the more it gripped me, and I can honestly say that my fascination with continuous sedation has never been greater than today.

This dissertation is the result of those four years of work. As such it represents my own process of thinking about continuous sedation. It by no means discusses in detail every ethically relevant aspect of continuous sedation, instead, it is an attempt to discuss what I believe to be some of the main issues.

I am, of course, indebted to a great number of people who helped me to realise this PhD dissertation.

First, I am eternally grateful towards Sigrid Sterckx, my main supervisor. With her advice and critical comments she has, without any doubt, helped me to become the researcher I am today. Fortunately, we had frequent opportunities to also discuss many issues outside of this PhD project (sometimes over nice Italian or Greek food). I greatly respect her as an academic, but possibly even more so as a person.

Next, I would also like to express my gratitude towards Freddy Mortier and Luc Deliens, my co-supervisors. They always provided insightful and valuable feedback, and provided an ideal environment for me to conduct my PhD. So it is safe to say that without them my PhD might not have been realised at all.

Someone who deserves an equal amount of gratitude is Julian Cockbain, who spent a large amount of time correcting my English. Thanks to him I do not only know what 'Dutchisms' are, I am also aware of the fact that my texts contain many. However, I also continue to value his views on the contents of my writings, and his part in this dissertation is therefore great.

The person who probably knows best just how much work it took to get the UNBIASED data gathered, is Livia Anquinet. Among us we drove across the whole of Flanders interviewing physicians, nurses, and relatives. We were always able to work very well together which allowed us to share the burden. For this, I owe her many thanks.

I would also explicitly like to thank Judith Rietjens, Tinne Smets, Martine De Laat, and Eric Mortier, who have all been my co-authors on one or more publications. I thank them for their time, and their willingness to share their knowledge and expertise with me. A great many thanks also to all the members of the UNBIASED consortium. Participating in this consortium has been a wonderful and greatly instructive experience.

Throughout my PhD I had the opportunity to meet many strong women. Among them are Farah and Aurélie with whom I had the privilege to share an office for most of my PhD. We had many inspiring conversations, and I often regret having moved to a different office.

Finally, I would like to thank some people in my personal environment who have helped me greatly. Thank you to my father and his wife, Peter and Manuela, and to my mother and her husband, Marina and Siegfried. They have always given the moral support that was needed to finish this dissertation.

Quite possibly the strongest and most impressive woman I have ever met, is my wife, Leonie. Her role in getting this PhD finished should not and can not be overestimated. She gave me support when I needed it, and understanding when I had to spend nights and weekends working. She is also a great mother to the newest woman in my life, my daughter Martha, whose smile is often just what the doctor ordered.

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Part 1

Background and introduction

Chapter 1
Introduction

In one of his writings, Woody Allen famously remarked:

> It's not that I'm afraid to die, I just don't want to be there when it happens (Allen 1975, 57)

Though, of course, said jokingly, this quote contains a number of interesting ideas. For one, it points out that dying may not be very pleasant, i.e. it is not something you want to experience. This is confirmed by the facts which show that although fast and painless deaths occur, this has become more and more rare due to advances in medical technology. Research from Flanders (Belgium) indicates that, in 2007, only 31.9% of all deaths could be classified as 'sudden' (Bilsen et al. 2009), which means that more than two thirds of all people dying that year experienced some sort of dying trajectory. Furthermore, these dying trajectories are often accompanied by some degree of physical or psychological suffering (e.g. Lynn et al. 1997; Fainsinger et al. 2000). More recent research shows the same picture, or as Steindal et al., who carried out a study of pain at the end of life, have noted: 'Pain is a highly prevalent symptom among dying hospitalized patients' (Steindal et al. 2011, 771)

Dying remains an unpleasant experience, although advances in palliative care and pain management have indeed made a pain-free end of life an achievable goal for patients. In many cases, however, a patient's suffering is so severe that 'normal' palliative care is not able to relieve all suffering, which leads physicians to make more far-reaching decisions, such as increasing medication to a potentially life shortening dose and, in countries where this is legal, euthanasia and physician-assisted suicide. Another end-of-life practice when suffering at the end of life becomes very severe is the administration of sedative medication with the aim of reducing a patient's consciousness until the patient dies, thereby making sure that she no longer experiences any suffering. One could call this practice continuous sedation at the end of life (CS). As it often amounts to putting a patient into a permanent coma until she passes away, this technique is, quite literally, a way to prevent people from being there when they die, or at least to not be present mentally.

1.1 The definition of sedation

It must be noted that there is no single concept of or definition for CS. This is more than just a mere inconvenience and is at the centre of many of the debates surrounding CS. In

ethical reflection, the way one defines something often guides the way one thinks about the issue, and in empirical research all findings relating to a certain practice must be interpreted by relating the findings to how that practice is defined in that particular piece of research. In incidence studies, for example, if one uses a broader definition (e.g. to include all instances of continuously and medically induced loss of consciousness), one is guaranteed to find very different results than if one would adopt a more specific definition. This, in my opinion, partly explains why studies into the incidence of the practice in countries such as Belgium, The Netherlands and the UK show significant differences, both between the countries (Anquinet et al. 2012) and within the same country. However, as this issue of definition is central to thinking about sedation, I will not elaborate on it here, but will postpone the discussion until the next chapter where the conceptual framework surrounding sedation is dealt with in depth.

1.2 Legality of continuous sedation

The question is sometimes raised as to whether continuous sedation at the end of life is currently a legal practice. This of course depends very much on the jurisdiction one is in, and I will not go into the many legal specifics. I will, however, say a few words.

First, as will be clarified in the next chapter, CS can, like all medical practices, be performed voluntarily (on patient request), non-voluntarily (without request because this is not possible) or involuntarily (without asking a competent patient when there is time to consent or even providing CS *against* a patient's wish). It is clear that the legality of providing a far-reaching practice such as CS *against* a patient's explicit request or without asking a competent patient is not in doubt: this is legally not allowed. Therefore, in this short section on legal issues pertaining to CS, I will talk only about CS that is either administered voluntarily or non-voluntarily.

The common view seems to be that, at least for Belgium and The Netherlands, continuous sedation is currently legal. CS is said to be a form of symptom control and as such not much different from other types of symptom control, all of which are legally permitted. Thus, CS is said to be 'normal medical practice' and therefore to fall within the range of practices a physician is legally allowed to employ. This is, for example,

stressed in a Dutch national guideline (KNMG 2009), as well as in a recent ethical advice by the Belgian organisation 'Zorgnet Vlaanderen'.[1]

There are, of course, other voices in this debate. Some commentators, such as Gevers (2003), claim that although CS might be symptom control, there are still reasons to be cautious and watchful. As he puts it:

> however, terminal sedation is an extreme measure of symptom control and in some situations the line between what is and is not responsible medical care may be thin. (Gevers 2003, 366)

It is therefore maintained by some authors that the legal situation regarding CS is not yet clearly settled, at least not in Belgium and The Netherlands. It is assumed that CS is legal in view of its similarity with other acts of symptom control, but this is not stated explicitly in the law. For Belgium, it is interesting to note that in 2002, when the law on euthanasia was in its final stages of discussion, the Belgian Council of State, in its advice on the content of that law (Advice 2-244/21),[2] noted that the law was silent on 'sedative care', where a patient is put into a sleep until she dies. The Belgian Council of State considered this to be a defect in the euthanasia law and recommended that the difference between euthanasia and 'sedative care' should be clarified, so that the legal status of 'sedative care' would be clearer. This advice by the Council of State was not followed, and so an opportunity to settle the legal situation regarding continuous sedation in Belgium was missed.

Sometimes it is also claimed that, under current laws, CS might even be illegal. This is for example argued by Evelien Delbeke, who notes that CS can do more harm than potentially shortening life. Even when life is not shortened, CS still takes away a patient's consciousness and this can constitute a harm that is sufficient for criminal prosecution (Delbeke 2013 *forthcoming)*. Most controversial are those cases of CS where artificial nutrition and hydration (ANH)[3] are withheld since life-shortening is then said to be more likely. In this regard it is often claimed that it is important to legally

[1] This is an employers' organisation in Flanders (Belgium) which represents more than 500 entities, such as hospitals and care homes for the elderly. The organisation represent a large proportion of the hospitals in Flanders and its opinions therefore have significant impact.

[2] The Council of State is the Supreme Administrative Court in Belgium and, as one of its tasks, it analyses all proposed laws that are to be passed and issues an advice on what it believes may be problems and shortcomings that should be dealt with before that particular proposed law is passed. However, the advice issued by the Council of State is not binding.

[3] Sometimes referred to as clinically assisted nutrition and hydration or CANH.

distinguish the decision to continuously sedate from the decision to withhold ANH. If CS is legally justified, and, separately, withholding ANH is also legally justified, then the combination is too. This issue will be discussed further below.

Some forms of CS are clearly more legally controversial than others, and many attempts have been made to clarify which conditions need to be fulfilled for CS to be performed. As mentioned earlier, arguably to some extent there is a consensus on this issue. However, only the Dutch national guideline has any legal ramifications, as the head of the Dutch Public Prosecutors has officially stated that he sees no reason to prosecute a physician who follows the guideline. Therefore, while following the guideline guarantees freedom from legal prosecution, non-adherence to the guideline does not imply that one is guilty of a crime. In 2012 the Dutch local court of 's-Gravenhage issued a verdict on a case involving a nurse who had illegally collected morphine and midazolam and had administered these to his dying father to make him unconscious until his death.[4] In administering the drugs, the nurse had clearly not followed many of the Dutch guideline's recommendations and this was acknowledged by the court. However, the court judged that, even though the national guideline was not followed, the medication was administered in accordance with the current medical insights and the nurse was cleared of all charges. This at least shows that what the Dutch national guideline describes is not the *only* legally permissible way to administer continuous sedation at the end of life, and so clarity is still lacking.

1.3 A seeming consensus

Regarding ethical acceptability, one sometimes gets the impression that some degree of consensus exists that continuous sedation at the end of life is an acceptable way to relieve otherwise intractable suffering. In research by Simon et al., 477 members of the German Academy for Ethics in Medicine were asked about their opinions regarding continuous sedation, and 98% 'regarded terminal sedation in dying patients with treatment-refractory physical symptoms as acceptable' (Simon et al. 2007, 1). This is also confirmed by more and more guidelines that have been and are being drafted concerning sedation at the end of life, the most important being a Dutch national

[4] BV6482, Rechtbank 's-Gravenhage, 09/925370-08 issued on 16 January 2012. Available at http://jure.nl/bv6482.pdf [last accessed 3 January 2013].

guideline (KNMG 2009), a Flemish[5] guideline,[6] a section in the 'Code of Medical Ethics' of the American Medical Association (AMA) (Levine et al. 2008), a guideline issued by the European Association for Palliative Care (Cherny & Radbruch 2009), and a guideline by de Graeff and Dean (2007). These guidelines all consider continuous sedation at the end of life to be acceptable, with the American guideline even claiming that: 'it is the *ethical obligation* of a physician to offer palliative sedation to unconsciousness as an option for the relief of intractable symptoms' (Levine et al. 2008, 6, emphasis added). As noted earlier, of these guidelines, only the Dutch guideline has any legal effect, but despite the others having no legal power, these guidelines provide a good representation of what one could see as the standard view on sedation, as these guidelines are in themselves based on a consensus of a large number of experts from different fields. These guidelines are also often claimed to be necessary (Vissers & Hasselaar 2010), and research from The Netherlands has shown that the Dutch national guideline is well known to physicians there, and has even led to an improvement of practice (Hasselaar et al. 2009).[7] Arguably, guidelines play an important role in contemporary discussions of sedation. Although I will not be able to discuss all points, as this would take us too far from the core ethical issues, some aspects common to many guidelines will be discussed below.

No intention to shorten life

All of the guidelines that I am aware of maintain that the goal of CS should always be to relieve distressing symptoms and never to shorten life. The AMA's Code of Medical Ethics, for example, holds that: '[p]alliative sedation must never be used to intentionally cause a patient's death' (Levine 2008). The Dutch national guideline likewise emphasises that CS should not be used with an intention to hasten death, and considers this one of the significant differences between CS and euthanasia. This issue of intentionally causing death will be elaborated upon further on in this introduction under 'CS and life-shortening', as well as in chapter 6 of this dissertation.

[5] Flanders is the Dutch speaking part of Belgium.

[6] Issued in 2010 by the Federation for Palliative Care Flanders (FPZV), and revised in 2012. The guideline is available at http://www.pallialine.be/accounts/129/docs/richtlijn_palliatieve_sedatie.pdf.

[7] To be more precise, this research showed that, after the introduction of a nationwide guideline, the recommendations made in the guideline were increasingly being followed (e.g. the use of benzodiazepines for sedation). The researchers worked on the assumption that the guideline constituted good medical practice and that therefore higher adherence to the guideline could be interpreted as an improvement of medical practice. This is, however, only assumed and not demonstrated in the article by Hasselaar et al. (2009).

CS as a 'last resort'

Something that is also stressed by most guidelines is that, in view of the seriousness of permanently taking away consciousness, continuous sedation at the end of life should be a 'last resort'. This is often achieved by recommending that CS should only be initiated when the patient is suffering from so called 'refractory' symptoms, which are symptoms that (1) cause a great deal of suffering, but (2) are no longer responsive to standard treatments, or existing treatments take too long to work properly, or the treatment is accompanied by unacceptable side-effects. This concept of a 'refractory' symptom therefore makes explicit that sedation should only be used when all else fails. Note, however, that although there is agreement that refractory symptoms are the only correct indications for continuous sedation, the guidelines differ in what they suggest can constitute a refractory symptom. This is discussed further below.

However, regarding the use of CS as a last resort, research indicates that in Flanders (Belgium) in 2007 the practice was used in 14.5% of all deaths (Chambaere et al. 2010), in the UK in 2007-2008 it was used in 16.5% of all deaths (Seale 2009) and in The Netherlands the incidence of sedation has risen from 8.2% of all deaths in 2005 to 12.3% in 2010 (Rietjens et al. 2008; Onwuteaka-Philipsen et al. 2012). It should be noted that, for the Belgian research, the results only relate to Flanders (i.e. the Dutch speaking region). As it is sometimes suggested that the incidence of sedation is higher in Wallonia (Van den Block et al. 2009) – the French speaking part of Belgium – it is likely that the incidence of continuous sedation for the *whole* of Belgium is higher than the estimated 14.5%. These studies all use a broad descriptive definition of continuous sedation, with the practice being defined as covering all cases where a patient is continuously kept in a deep coma until death by the use of one or more drugs. Claessens et al., who used a narrower definition of CS, found an incidence of only 7.5% in Flemish palliative care units (Claessens et al. 2011). One could argue about what definition is correct to use for research, but such matters aside, these studies, at least, show that continuous sedation is a practice that is currently being used by many physicians and that keeping patients in a medically-induced continuous sleep at the end of life is not uncommon.[8] This

[8] Almost all research currently done of course relies on physicians' recollections of what drugs were administered and with what intention, and also on physicians' assessments of the effect these drugs had (in terms of life shortening or reduction of consciousness). The risk in all such research is that physicians have poor recollection (recall bias), and also that physicians have made incorrect assessments about the effects of the administered drugs on the patient. This could lead to an overestimation or underestimation regarding the role the drugs played in reducing patients' consciousness, but this is a difficulty that all interview- or questionnaire-based research faces.

therefore raises some questions about CS being always a last resort, as, in view of the advances in medicine and palliative care, it seems unlikely that in all these cases there was no other option than to use CS.

CS only in the last days of life

That sedation should be used only in the last days of life is another issue that is common to all of the guidelines that I am aware of (and also to many definitions of CS, as will become clear from the next chapter). This requirement is central to many guidelines as they all stress that CS should be distinguished from euthanasia, since in sedation, the guidelines maintain, there is no shortening of life, and even if there would be, this would be wholly unintentional. If, however, CS were to be used for patients with a long life-expectancy, it could cause some life shortening, thereby blurring the distinction between continuous sedation and euthanasia. What constitutes 'the last days of life' is far from always clear. Guidelines such as the AMA's Code of Medical Ethics merely require that sedation be used for terminally ill patients, without specifying what 'terminally ill' means. The Flemish guideline is more specific and states that sedation should only be considered for 'dying patients', which it defines as 'patients with multiple signs of the dying phase'. The Dutch national guideline is the most explicit and requires that CS should only be initiated in patients whose life-expectancy is less than two weeks.

Many studies have been done and these indicate that CS is indeed, as current guidelines recommend, generally only used shortly before death. In Flanders (Belgium), for example, in 2007, 91% of all continuously sedated patients survived less than a week (Chambaere et al. 2010), while in The Netherlands in 2005, this was 94% (Rietjens et al. 2008). This being said, there were still cases where the patients under continuous sedation survived longer than two weeks.

Proportionality

Another issue that is common to all of the guidelines that I am aware of is proportionality. Most guidelines acknowledge that taking away consciousness is a serious matter and should only be done when there is no other option (i.e. the last resort requirement mentioned above), and that even in those cases, a patient's consciousness should not be reduced any more than is necessary to relieve her of distress. Proportionality is understood in many guidelines as requiring that the medication should be titrated against the symptoms a patient suffers from. The

principle of proportionality can also carry great moral weight and even serve as a ground of justification as it portrays sedation as the lesser of two evils.

Whether proportionality is indeed a guiding principle in decisions to use CS is difficult to measure in research as it requires knowledge not only of the physician's intention, but also of many case specifics in order to correctly interpret the dosages that are given. Some research has been done, for example by Swart et al. (2012), which showed that physicians have different interpretations of what it means to sedate 'proportionally'. Some physicians interpreted 'proportionality' in the way that most guidelines seem to understand it, namely as involving starting with a low dose of sedatives and gradually increasing the dosage if required. Other doctors felt that sedating 'proportionally' required starting with a deep sedation to make sure that patients do not suffer any more. This is a different view of proportionality and Swart and colleagues concluded:

> However, proportionality seems to be understood as being more than strictly titrating drugs to the relief of refractory symptoms. We found that physicians use a multidimensional concept of proportionality, in which other factors also play a role. (Swart et al. 2012, E363)

This would seem to suggest that the requirement of proportionality, as understood by most guidelines, is not always met in practice. What proportionality means, and whether it can adequately be invoked in CS, is discussed further in chapter 7.

Artificial nutrition and hydration

Continuous sedation at the end of life is sometimes accompanied by withdrawing or withholding artificial nutrition and hydration (ANH), and this issue is touched upon by nearly all guidelines. The consensus in the guidelines seems to be that one can withhold ANH from a sedated patient, but that this is a separate decision and, as such, must itself be justified. However, even when one withholds artificial nutrition and hydration, most guidelines maintain that the majority of patients have already stopped taking in food and fluids before the sedation starts, and, moreover, that patients receiving CS have a very short life expectancy so the potential life shortening is minimal or non-existent. This issue of combining CS with withdrawing or withholding ANH is also the topic of heated ethical debate, a debate which will be elaborated upon further on in this introduction.

From research, we know that, although the decisions to sedate and to withhold ANH are said to be two different decisions, they accompany each other in most cases. Research

by Claessens et al. (2011) showed that in palliative care units in Flanders, only 15% of patients received artificial hydration until death,[9] because most patients had stopped taking in fluids before being sedated (Claessens et al. 2011). Other research from Belgium showed a somewhat higher percentage with ANH being withheld or withdrawn in 57% of cases (Chambaere et al. 2010). Research in The Netherlands showed similar percentages as, according to Rietjens et al. (2008), ANH was withheld there in 66% of all sedation cases.

Patient request or consent

A final element of agreement amongst most current guidelines is that CS should not only be justified by a patient's needs (relief of refractory symptoms), but also as much as possible by a patient's autonomy. Informed consent by the patient or, if that is not possible, by the patient's legal representative, is recommended by all guidelines. In some cases, informed consent may not be possible, for example where a carotid artery has ruptured requiring rapid action by the physician, and the use of sedation without consent is not excluded in such cases.

Research, however, teaches us that, although recommended by all guidelines, at least for Flanders (Belgium) a request or consent is rare. In Belgium in 2007, there was a request or a consent to continuous deep sedation[10] in only 30% of all sedation cases (Chambaere et al. 2010). Similar research from The Netherlands shows that although CS is more often discussed with the patient, it is far from always discussed. This is a surprising finding, especially since the Dutch study looked only at continuous *deep* sedation *without* ANH (i.e. the most extreme form of sedation).

1.4 The ethical justifications of CS

The way in which most guidelines describe how CS should be performed is, of course, by no means accidental: it allows for the ethical principles of autonomy, proportionality and double effect to provide ethical justificatory grounds for the practice.

[9] It should be noted that this was a small scale study with 15% representing 3 patients.
[10] Note that this research looked only at continuous *deep* sedation.

That guidelines prescribe that physicians using CS should not have the intention to shorten life, allows the Doctrine of Double Effect (DDE) to provide ethical justification in cases where life has potentially been shortened. The application of DDE will not be elaborated upon here, as it is the topic of chapter 6 of this dissertation. In that chapter, it will be questioned whether DDE can in fact unproblematically justify CS.

Moreover, all the published guidelines require that, in CS, sedatives be administered proportionally to the severity of a patient's symptoms. This allows the ethical principle of proportionality to come into play, a principle which recognises that, since refractory symptoms cause great distress, CS – although a far reaching practice - may sometimes be considered to be a proportional response. For the principle of proportionality to apply to CS, the practice has to be the least invasive way to achieve a state of pain relief. If a less invasive alternative is available which yields the same effect, CS cannot be claimed to be a proportional response to suffering, as it is then more invasive than is necessary. This is precisely why many guidelines stress that in CS one should aim at the lowest degree of sedation necessary. However, as will be argued in chapter 7 of this dissertation, how deeply a patient is sedated is rarely measured, and when one is not certain that a particular dose is indeed high enough to obtain the desired effect and yet low enough to be the least invasive way to obtain that effect, it cannot be guaranteed that the physician has acted *proportionally* in that case. This issue is discussed in greater detail in chapter 7.

Finally, the requirement that consent must be obtained wherever possible allows for the principle of autonomy to come into play. This principle holds a central role in the medical ethics of today, where it is increasingly recognised that there have to be strong reasons to override a competent patient's wishes. In this respect, it must be noted that 'autonomy' can only provide justifications for cases of CS where a competent patient freely chooses it (or at least consents to it) or cases where a patient's legal representative chooses it (thereby providing a substitute for the patient's autonomous choice). Research from Flanders (Belgium) and The Netherlands indicates that this is far from always the case. Moreover, one could argue about the extent to which patients can really autonomously choose continuous sedation at the end of life. As discussed above, according to most guidelines there has to be a medical indication for CS to be initiated, namely a refractory symptom. As I discuss below, what constitutes a refractory symptom often requires input from the patient herself, but it still has to be diagnosed by a physician. For a physician, it is therefore always possible to ignore a request for CS on the basis that there is no correct medical indication for it. Of course, this is true for all so-called positive requests in Belgium; physicians can never be obliged to perform a certain practice following an autonomous request if they believe there to be reasons not to perform that practice. Another issue to consider is that many guidelines require that

CS only be used as a 'last resort' when there are no other remaining options.[11] This may raise doubt as to the extent to which patients can autonomously choose CS, since the practice can only be considered when one has no other real options to choose from. Countries where euthanasia or physician-assisted suicide (PAS) is legal are somewhat different in that in these countries, in situations where CS and euthanasia or PAS are possible, a patient often does have other options, although these are at least equally invasive.

1.5 CS and life-shortening

It is clear from some of the previous discussions that there is often a difference between the way CS should be performed according to the standard view (voiced in guidelines), and the way in which the practice is actually performed. When reading currently existing guidelines, one gets the impression that CS is unproblematic, but this often seems to be merely an idealised image which does not always reflect current medical reality. Ethical questions therefore remain (e.g. Gillick 2004; Battin 2008). One of the most profound ethical issues is whether the practice of continuously sedating patients at the end of life has a certain or potential life-shortening effect.

It is commonly argued or quite simply claimed that continuous sedation does not shorten life (e.g. de Graeff & Dean 2007; KNMG 2009). This focus on CS not shortening life is far from accidental, as the risk of CS shortening life or as being used as a backdoor way to shorten life is often seen as the most problematic aspect of sedation. Precisely because of its potential for life shortening, CS has been described as being 'slow euthanasia' (Billings & Block 1996). However, if CS were not to shorten life, or at least not intentionally to do so, the practice would be distinct from euthanasia and, as the suggestion goes, would pose no real ethical problems. As de Graeff and Dean have stated:

[11] Note that this does not always mean that there are no options, but very often that there are no 'real' or 'less invasive' options left. Though to simply do nothing and let the patient die a horrible death may always be an option, it is clear that in most cases it is not a 'real' option. Furthermore, in those countries where it is legal, euthanasia may at times also be an option to relieve a patient's distress, but as this practice is no less invasive than CS it is clear that in those cases CS can still be seen as a 'last resort'.

> The decision to offer sedation to relieve intolerable suffering during the last weeks of life presents no distinct ethical problem, provided that there is no intention to hasten death. (de Graeff & Dean 2007, 76)

Some authors, however, question whether one can in fact convincingly claim that CS does not shorten life (e.g. Battin 2008). First, an interesting Dutch study has shown that some physicians who used continuous sedation believed the practice to have shortened life (Rietjens et al. 2008), while in a Belgian study some physicians even indicated that they had used continuous sedation *in order to* shorten life (Chambaere et al. 2010). Other research from Belgium indicates that nurses involved in continuous sedation often believed that in particular cases life was in fact shortened. These nurses estimated that there was a potential life shortening in 51.2% of all sedation cases and *certain* life shortening in 44.4% of sedation cases (Inghelbrecht et al. 2011). The same nurses also believed there was a co-intention to hasten death in 48.4% of sedation cases and an explicit intention in 28.4% of cases (Inghelbrecht et al. 2011). Of course, this does not mean that life was actually shortened but merely that some physicians and nurses at least *felt* or *perceived* that it was.[12] The least one could say is that this goes against what is recommended in the guidelines discussed above. Furthermore, even if life was not in fact shortened, if there was an intention to hasten death this would already be in ethically murky waters according to some guidelines.

That life-shortening actually occurred is, furthermore, far from impossible, and it is safe to say the verdict is still out on whether continuous sedation does sometimes shorten life. It is true that some studies are often cited that supposedly show that there is no difference in survival rate between sedated and non-sedated patients (Ventafridda 1990; Stone et al. 1997; Sykes & Thorns 2003; Morita et al. 2005), but these studies, I believe, do not settle the argument once and for all. It has been argued that the methodology of these studies is such that they are not absolutely conclusive, as there might be important differences between sedated and non-sedated patients that are missed and that invalidate the research. Stone and colleagues, who did such – often cited – research comparing the survival rates of sedated and non-sedated patients, concluded that:

> The only way that survival times could be directly compared would be to randomly and blindly allocate patients who were felt to require sedation to either

[12] It needs to be stressed that this research concerned only continuous *deep* sedation. Since this is an extreme form of continuous sedation at the end of life, it is likely that the perception of life-shortening would have been less had lighter sedation been included.

> receive it or not and to observe what happened. This would be ethically unacceptable. (Stone et al. 1997, 144)

The results of such studies are highly dependent on the definition one uses for sedation and the population one researches. If one looks only at cases where life is less likely to be noticeably shortened (e.g. patients in their last hours or days, or patients still receiving food and fluids), it is not surprising that no life-shortening is seen. Moreover, showing that there is no statistically significant difference between sedated and non-sedated patient groups does not necessarily mean that life cannot be or have been shortened in individual cases. Sykes and Thorns, for example, conducted a study in which they concluded that sedation does not shorten life. This was said to be conclusive, but even in this research:

> It was possible to identify 2 cases in which, because of the severity of the patients' delirium, the rate of increase of sedative dose was high enough to raise concern that life might have been shortened, and in one of these cases the attending physician clearly foresaw this risk. (Sykes & Thorns 2003, 344)

This is why, in my view, one cannot simply claim that CS does not shorten life. In many individual cases it might be clear that life shortening does not occur, but this does not apply across the board.

One could of course interject and say that most authors and guidelines today would perhaps agree that sedation *could* be used to shorten life, for example by giving extremely high dosages or by using it for patients with a long life expectancy, but that this is not the *correct way* to use sedation. The standard view seems to be more nuanced and simply claims that:

(1) *Standard view:* If continuous sedation is used appropriately, it does not shorten life.

A similar view is voiced in the Dutch National guideline. There it is claimed that: 'there is no evidence that continuous deep sedation, if carried out in accordance with good medical practice, does shorten life' (KNMG 2009, 11). Here, however, it is unclear what 'appropriately', or 'good medical practice' mean, so it is important to further qualify this in order to make the standard view a meaningful statement. 'Appropriately' often seems to mean 'the way it should be performed', and the best recommendations of how CS should be performed (i.e. of what constitutes 'good medical practice') are, presumably,

the existing guidelines. So if one rephrases the standard view, taking this into account, one obtains the following:

(2) *Guideline view:* If continuous sedation is used according to existing guidelines, it does not shorten life.

It is clear that this is still unproven, and not entirely consistent, since there are some differences between the various guidelines, but I shall make abstraction of this difficulty. The point I want to make is that the standard view is somewhat tautologous. Janssens et al. (2012) have, in my view correctly, argued that the authorative Dutch national guideline makes certain recommendations precisely in order to guarantee that the practice it describes does not shorten life. An example is the recommendation that sedation can only be used for patients with a life-expectancy of less than 2 weeks. The Dutch guideline is by no means unique in this respect, as all of the guidelines have recommendations that seem to be included merely for the purpose of excluding any life-shortening practice from the definition of CS. Thus one can rephrase the guideline view as follows:

(3) *Tautology*: If continuous sedation is used in a way that is guaranteed not to cause shortening of life, the practice does not shorten life.

Formulated in this way, it becomes evident that the standard view often translates into a statement that is not only true, but is *necessarily* true. What initially looks like a meaningful statement, does not actually generate any meaningful information on the ethical problems relating to continuous sedation at the end of life. The statement 'continuous sedation does not shorten life' is therefore, in my view, either doubtful (if one takes 'continuous sedation' to mean all sedation that is administered continuously at the end of life), or devoid of meaning (if one takes 'continuous sedation' to mean continuous sedation performed in such a way as not to shorten life).

Indeed, many aspects of sedation are not as they are portrayed in the idealised image and many ethical questions do remain. The issue of whether or not the practice shortens life is not yet settled, and even if CS did not shorten life, it is important to keep in mind that it is a far reaching medical practice since it not only reduces or takes away a patient's experience of suffering, but also reduces or takes away every experience the patient could have, including the positive ones, as well as the possibility to communicate. In completely removing a patient's consciousness, the practice is said to have some similarities with euthanasia (Billings & Block 1996). Moreover, even though the standard view maintains that CS can be partly justified by autonomy, much work

has to be done in Belgium at least where, as was shown, request or consent is rarely made or obtained.

1.6 CS and withdrawing or withholding ANH

As already mentioned above, patients receiving continuous sedation at the end of life often receive no ANH. In some cases, patients have already stopped taking in food and fluids before sedation is initiated. In other cases, patients are still eating and drinking when sedation is initiated, but it is decided that ANH will not be given once the sedation starts. In a third scenario, patients are already receiving ANH before sedation is initiated, but it is decided to withdraw it when sedation starts.

It is clear that when ANH is not given, the practice of CS becomes more controversial. If sedation were to last a somewhat longer time (e.g. a couple of weeks), and no artificial nutrition and hydration would be given, this lack of ANH could undoubtedly cause the patient's death. Or, as Battin has noted: 'in terminal sedation death typically results from or is accelerated by dehydration' (Battin 2008, 28). Indeed, withholding ANH at least heightens the impression that CS *could* have a life shortening effect, an impression that many guidelines are trying to avoid. In this respect, a two-fold argument is often made. First, the argument goes, stopping all intake of food and fluids is a natural part of the dying process. Indeed many patients naturally stop eating and drinking, and in this respect, it would be unethical to force ANH on them while they are continuously sedated until death. As Claessens et al. (2008) have argued:

> If a patient shows signs of imminent death (e.g., loss of appetite, decreased food/fluid intake) before sedation, then it seems irresponsible and unethical to hamper the natural dying process by administering artificial food or fluid during sedation. (Claessens et al. 2008, 328)

Second, one could argue that, even with patients who do not stop all intake of food and fluids, life is not actually shortened since CS should only be initiated in the final days before death, and this period is too short for the withholding of ANH to have any effect. By using this two-fold argument, many guidelines allow for sedation to be combined with withholding ANH. In fact, the Dutch national guideline actually *recommends* ANH to be withheld or withdrawn in CS as, according to the guideline, continuing it is often futile. Most guidelines do however stress that if ANH is to be withheld, this has to be considered to be a completely different decision, separate from the decision to sedate.

The ethical debate on this issue still rages on, as many questions remain regarding the arguments outlined above. First, it is indeed true that many patients themselves stop taking in food and fluids, and to some extent one could claim that this is a 'normal' part of the dying process. The pertinent question, however, is not whether patients actually stop their eating and drinking, but why do they do this? Many patients might stop because they have become unable to take in food or fluids, or because it has become a burden, but it is not clear that this means that these patients do not *want* to be hydrated or to live as long as possible. Furthermore, even if stopping food and fluids intake is a 'natural' part of the dying process, it is still far from clear that it is therefore in any way good, or that providing ANH would be unethical. In a similar vein, one could claim that pain is a 'natural' part of dying, but it would be wrong to argue that pain is therefore good and should not be interfered with. Indeed, palliative care is devoted to avoiding many of the 'natural' parts of dying.

Second, it is sometimes questioned whether using sedation only shortly before death does indeed guarantee that if ANH is withheld there is no life-shortening. Physicians are notoriously bad at predicting life-expectancy (e.g. Wilson 2005; Clarke et al. 2009), so it is always possible that sedated patients will or could live longer than predicted. Life-shortening thus remains a possibility in many cases of CS where ANH is withheld. Furthermore, it is unclear what period of time it takes for the withholding of ANH to have any effect in dying patients. The assumption in the Dutch guideline seems to be that it takes at least two weeks to die of dehydration or lack of nutrition. However, this assumption is based on the period it takes for lack of food and fluids to be the *sole* cause of death in *healthy* adult humans. It might be the case that in dying patients who need sedation (and are thus, by definition, in a very poor physical condition), withholding ANH could have a lethal effect in less than two weeks. Moreover, that withholding ANH cannot be considered the actual and *sole* cause of death in short time periods, does not mean that it cannot have *any* effect on the timing of a patient's death.

Finally, whether CS without ANH is to be considered one decision or two distinct decisions is also a topic of debate. According to those defending the idea that it involves two separate decisions, CS constitutes what Cellarius calls a 'simple whole' (Cellarius 2011), where two acceptable parts form an acceptable whole. If sedation can be justified and withholding ANH can also be justified, then the combination of the two is automatically justified. Withholding ANH could then, for example, be justified on the grounds that it is futile for a dying patient. This quickly becomes tricky as, for example, the fact that the patient is unconscious and has no experiences whatsoever cannot be used to argue that ANH is futile, as one decision would then serve to justify the other. Furthermore, as Søren Holm argues (Holm 2013, *forthcoming*), if withholding ANH would cause some symptoms to appear, ANH is not futile, as it would then serve to hold back

those symptoms. Other commentators have argued that trying to separate the decisions is wrong and merely clouds what CS without ANH is actually about. Helga Kuhse, for example, has argued that first reducing consciousness and then taking away life-sustaining treatments are merely two steps in the same process leading to the inevitable death of the patient (Kuhse 2004). Moreover, the fact that a person is brought into a state of reduced consciousness fundamentally changes the nature of withholding ANH. Stopping all eating and drinking before CS allows the patient to change her mind, while permanently reducing a patient's consciousness first, deprives her of the possibility to start taking in food and fluids again, should she want to do so.

It is therefore clear that the combination of CS and withholding ANH is far from uncontroversial and the debate on this issue rages on.

1.7 Refractory symptoms and existential suffering

Continuous sedation at the end of life can be initiated for various reasons. As already noted above, most guidelines recommend that CS should only be indicated by so-called refractory symptoms. A symptom is refractory when there is no method other than continuous sedation that can be used for palliation or - if there is an alternative method - when the symptom cannot be alleviated within an acceptable time frame and/or without unacceptable adverse effects.

Regarding the first possibility, that a symptom is refractory when there is no alternative method for symptom relief, it is not always clear whether this means that the alternative method has to merely exist, or whether it has to be available. The latter interpretation seems to be preferable, since I think most would agree that denying a person symptom relief by continuous sedation merely because an unavailable, alternative method exists, would be wrong and even cruel. This interpretation has an important impact. Whether a symptom in a certain case is refractory or not then depends at least in part on geographical location. For example, hospitals in less developed countries or regions might have fewer available means and methods than hospitals in well developed countries or regions, thereby making certain symptoms refractory. The same, of course, also applies within countries, for example between different settings. A certain symptom might be refractory in a home-care setting, but non-refractory in a hospital setting (because different equipment or expertise is available).

When an alternative method for palliation is available, a symptom can still be refractory if this method does not provide relief within an acceptable time frame, or does so with unacceptable side-effects. Here too, what constitutes a refractory symptom is also dependent on something else, namely what a physician or a patient considers to be an unacceptable time-frame or unacceptable side-effects. The best judge of this, I believe that everyone would agree, is the patient herself or the relatives who have intimate knowledge of the patient's beliefs and values.

Available research indicates that most the common refractory symptoms are all distressing physical symptoms. Both a Dutch study (Rietjens et al. 2006) and a study from Taiwan indicated that the most common indications for CS are delirium, pain, dyspnoea, and fatigue. As such, the practice of CS differs from euthanasia and physician-assisted suicide, which are most commonly initiated for more psychological symptoms such as 'loss of dignity' and 'no prospect of improvement'. Some guidelines, such as the AMA's Code of Medical Ethics, therefore maintain that CS cannot be indicated when existential suffering is the ‘refractory symptom’. The AMA states:

> Palliative sedation is not an appropriate response to suffering that is primarily existential, defined as the experience of agony and distress that may arise from such issues as death anxiety, isolation and loss of control. Existential suffering is better addressed by other interventions. For example, palliative sedation is not the way to address suffering created by social isolation and loneliness; such suffering should be addressed by providing the patient with needed social support. (Levine 2008, 7)

Other guidelines do leave open the possibility that CS can be initiated for ‘mere’ psychological or existential suffering. The Dutch guideline notably argues that existential suffering can be a refractory symptom. Of course, the Dutch guideline also recommends that patients receiving CS should have a life-expectancy of two weeks at most, which causes the discongruity between the American and the Dutch guidelines to be smaller than it seems at first sight. Patients with less than two weeks to live can, generally speaking, be expected to be in poor physical condition, making it unlikely that there will be many cases where there is *only* existential suffering. The two week life-expectancy limit makes it possible for the Dutch guideline to consider existential suffering to be a refractory symptom. Research by Simon et al. among German experts in medical ethics complements this nicely, since this research shows that 61% of people with a medical background and 52% of experts without a medical background considered continuous sedation for existential distress to be acceptable. When combined with the withholding of ANH, the numbers remained high with a 55% acceptance rate for experts with a medical background and 44% for those without.

However, when it concerned patients with an unfavourable prognosis - rather than actually dying patients - the acceptance rates dropped significantly.

The problem with existential suffering being considered to be a refractory symptom seem to lie in determining whether it is in fact refractory. Can one be absolutely certain that certain psychological suffering will not be relieved by using a different method or technique? There seems to be a wider range of methods available to deal with psychological or existential suffering than there is to deal with suffering with a more somatic origin.

Of course, some commentators take an additional step and even question whether existential suffering can be considered a refractory symptom at all (e.g. Materstvedt & Bosshard 2009). Indeed, although there is suffering, existential suffering is not in any way a medical state one can be said to be in or a manifestation of an underlying condition or disease. Existential suffering is therefore fundamentally different from suffering caused by diagnosable psychiatric or psychological conditions. It concerns, for example, feelings of non-worthiness, loneliness, and fear. Classifying things such as fears and emotions as symptoms, often seems to be a way to bring these things into the medical domain, a technique that has already been described and criticised by Ivan Illich in his famous *Medical Nemesis* (Illich 1979). Indeed, there often seems to be a tendency to portray existential suffering as a symptom that can be described and measured in a more or less objective way. A nice example is an article by Schuman-Olivier et al. who argue that CS can be initiated for existential distress and who develop a classification system, which differentiates among three different types of existential distress, thereby giving it an objective air (Schuman-Olivier et al. 2008).

The remarks made in the previous paragraph should not be interpreted as a denial of the seriousness of existential distress. People at the end of their lives should have the right to be relieved of all unnecessary pain, whether it be of somatic or existential origin, but I wonder whether it is in fact always beneficial to turn everything into a medical problem. I would say that, quoting Materstvedt, we should be careful not to: '[charge] palliative care with the task of finding a medical response to existential suffering' (Materstvedt & Bosshard 2009, 626).

1.8 Doctoral disertation

The inadequacy or tautologous nature of the guidelines and the lack of a single generally accepted definition of what constitutes continuous sedation opens up the possibility of depicting the practice of CS in various different ways. CS has, for example, been depicted as a natural death, as an ethically preferable alternative to physician-assisted suicide, as a proportionate response to refractory symptoms, and as similar to the administration of heavy dosages of medication for pain-relief, where the intention can be said to be the relief of suffering with potential life-shortening as a mere side-effect. The goal of this doctoral dissertation is to bring to light some of the most common portrayals of CS, what their underlying reasons might be and what their normative impact is. Besides describing and discussing these depictions of CS, I will also analyse whether these portrayals are ethically valid. Finally, I will move from a discussion and ethical analysis of common depictions of CS to a research on how medical professionals actually experience the practice of sedation at the end of life.

Research questions

The overarching research questions for this doctoral dissertation are:

1) In what ways is continuous (deep) sedation until death portrayed?

1.1) Are these portrayals successful?

1.2) Why are some of these portrayals successful?

1.3) What is the ethical impact of these portrayals?

2) What is the ethical validity of these portrayals?

2.1) Do these portrayals survive ethical scrutiny?

3) In what way is the practice of continuous (deep) sedation until death experienced by medical professionals?

3.1) Does this experience match the portrayals discussed when answering research question 1 and 2?

Chapter 2: Defining continuous sedation

Before discussing several ethical and practical issues relating to continuous sedation at the end of life, it is important to discuss the various concepts that exist for the practice and the various definitions that are given for CS. The first part of this chapter therefore provides a descriptive overview of some of these concepts and definitions. I attempt to make clear that even defining sedation is a matter of discussion, as a definition is rarely morally neutral. The definitions currently used differ in that some are deliberately narrow, while others are deliberately broad. In a second part of the chapter, I will expand on the definition of sedation I will use. By referring back to the discussion in the first part, I want to make clear how my definition compares to other definitions and what the implications are of defining continuous sedation in the way I do. As I will argue for a broad definition that includes many types of continuous sedation cases, I will further divide what I define as CS into different types. Doing this is a crucial component of a sound moral argument on sedation as the different types of sedation differ in morally relevant ways.

Chapter 3: Introducing continuous sedation

This chapter is the last of the 'introductory' chapters in which more general issues relating to continuous sedation at the end of life are discussed. The chapter starts by noticing that the need for continuous sedation at the end of life lies in the presence of severe human suffering. Most of us would prefer to die peacefully and without suffering, and pharmacological interventions can bring us closer to that ideal. Indeed, some patients who died a comfortable death, might not have died so comfortably had they not received CS. A certain degree of consensus seems to exist that CS is an acceptable practice to relieve unbearable suffering in dying patients.

Nevertheless, many issues remain the topic of ethical debate. A first topic is the definition of CS (discussed in chapter 2). A second topic, which is dealt with in more detail in this chapter, is the issue of ANH. This is an issue of particular importance as CS is often performed without ANH, and this might make a life-shortening effect more likely. Some commentators have dubbed the decision to withhold ANH as completely separated from the decision to use CS, but this might constitute a salami-slicing technique (van Delden 2007). Moreover, it might cloud some of the most important aspects of CS.

Other aspects of sedation that are discussed in this chapter include the Doctrine of Double Effect as a justification for CS, the role and involvement of other parties in sedation (e.g. family members, nurses,...), and the concept of proportionality.

Finally, this chapter focuses on what it means for a practice to be considered a 'normal medical practice', and whether this would include CS. 'Normal medical practice', it is argued, is a practice for which professional guidelines are deemed sufficient to prevent potential abuses. Euthanasia and physician-assisted suicide are therefore to be seen as 'non-normal medical practices' as the Belgian and Dutch governments have drafted laws (i.e. regulations that do not emanate from within the medical profession) to avoid possible misuse and abuse. Whether professional regulations would suffice to prevent CS from sliding down a slippery slope towards abuse, is a topic of heated debate, and at least some commentators provide us with reasons for doubting that no external regulation is required for CS.

Chapter 4: Continuous deep sedation at the end of life and the 'natural death' hypothesis

This chapter starts from the observation that the incidence of continuous sedation in various countries is high, especially so since the practice is often claimed to be a mere 'last resort' option. The different factors influencing the popularity of continuous sedation and the fast growing incidence remain largely unknown. In this chapter, a hypothesis is brought forward, namely the 'natural death' hypothesis, according to which the incidence of continuous deep sedation is growing rapidly because the practice is often conceived of as allowing a 'natural' death. That continuous deep sedation is very often seen as leading to a 'natural' death is undeniably so, and is shown to be an idea that is present both among influential commentators in the debate, and among physicians and nurses dealing with sedation in their daily practice. Yet interesting questions that remained unanswered up to now are:

(1) What aspects of continuous deep sedation might make it similar to a natural death?
(2) What would be the consequences of it being similar to a natural death?

When analysing in more detail the aspects continuous deep sedation seems to share with a natural death, it is clear that the similarity is there only in *appearance*. While some aspects of continuous deep sedation make it look like a natural death, steps are sometimes *actively taken* to cultivate or preserve this appearance. That sedation is often made to look like something it is not, is first observed in this chapter, but will form a

thread throughout the entire dissertation, where we will look at other ways in which sedation has been portrayed.

This still leaves open the question as to why sedation is portrayed in this way? The answer seems to be that depicting continuous deep sedation in this way makes it easier for many health care professionals to cope with their involvement in the practice. This way of conceiving of continuous deep sedation seems to present it in a more ethically acceptable form. This can, however, only be said to be true if 'natural' death is an intrinsic good, which it does not seem to be. Indeed, some patients may want more 'natural' sedation, but others might prefer to die in a conscious state and may not want sedation. This is not to say that continuous sedation is wrong, but merely that its wrongness or rightness can not be assumed *a priori*.

Chapter 5: Is continuous sedation at the end of life an ethically preferable alternative to physician-assisted suicide?

Chapter 4 gave a first insight into the ways that the practice of continuous sedation can be portrayed, and how, by portraying the practice in a certain way, one can influence the moral acceptability of the practice. This idea is further explored in chapter 5, where we discuss one particular portrayal of continuous sedation, namely as an *a priori* morally preferable alternative to physician-assisted suicide (PAS).

Authors depicting sedation in this way often do so as part of an argument against legally or morally allowing (physician-)assisted suicide in any form. Indeed, if one could show that (1) continuous sedation achieves the same goal as PAS, and that (2) some elements of continuous sedation make it always preferable to PAS, this would lead to the inevitable conclusion that PAS is never the preferable way to relieve suffering. This argument, that the availability of continuous sedation makes allowing PAS unnecessary, has been used in the US Supreme Court case of *Vacco* v. *Quill*, and we will label this the 'argument of preferable alternative'.

As it turns out, there are multiple versions of the argument of preferable alternative, with each version stressing a different characteristic that supposedly makes continuous sedation preferable to physician-assisted suicide. One version sees CS as preferable, because the practice is already legal, allowing us to deal with severe suffering at the end of life without having to change the law (something which always comes at a certain risk, and especially when it comes to life or death matters). A second version holds that continuous sedation at the end of life has less or no risk at all of being a slippery slope. Third, some authors claim that sedation is morally superior to assisted suicide since

sedation is 'normal medical practice' and as such is compatible with a physician's role as a healer. A fourth version claims that the value of sedation is that it provides a compromise position and as such reconciles the opponents in a very heated debate.

Each of these versions of the argument of preferable alternative, I argue, is flawed in some respect, leading to the conclusion that although in some cases and for some patients continuous sedation is (morally) preferable, the practice cannot be claimed to be *a priori* preferable.

Chapter 6: Can the Doctrine of Double Effect justify continuous deep sedation at the end of life?

Chapter 4 discusses the way in which death after continuous sedation is portrayed as a natural death, while chapter 5 shows how certain aspects of sedation are sanitised and how the practice is often depicted as a morally unproblematic and even preferable alternative to physician-assisted suicide. Chapter 6 shows how another crucial aspect of sedation is the topic of a portrayal and/or sanitization, namely the intention with which sedation is performed.

It is often claimed that the physician's intention in performing continuous deep sedation is not to hasten death or to induce a coma, but is simply to relieve distress and nothing more. If life is shortened or a coma is induced, this is merely a side-effect. In this way, the practice of continuous sedation is set up to fall under the Doctrine of Double Effect (DDE), and thereby to be justified. As is shown in this chapter, this doctrine holds great moral force in medical ethics in general, and end-of-life ethics in particular.

This chapter therefore tries to answer the question as to whether the DDE really does apply, or indeed whether the 'classical form' of the doctrine applies since, as is shown, many different interpretations of DDE exist. Even when one restricts oneself to a classical and strict interpretation of DDE, it is still not clear how the doctrine applies to continuous deep sedation in the various proposals made in the literature. These proposals can, however, be grouped together into five categories, each of which is discussed in this chapter.

As it turns out, none of these proposals can be judged to be successful in justifying continuous deep sedation at the end of life. One of the main reasons is that, in general, the focus has been on the potential life-shortening effect of sedation, while the real harm of continuous sedation lies in the fact that, in its most extreme form, the practice

permanently and continuously takes away the capacity for *any* experience, both positive and negative.

This does not, however, mean that sedation must therefore be deemed to be unjustified. In fact, the most common application of DDE to continuous deep sedation turns out to be non-construable. What *appears* to be DDE reasoning, is in fact an argument from proportionality (i.e. choosing a lesser evil over a greater one). If this is the true justification for continuous deep sedation, it is misleading to keep relying on DDE.

Chapter 7: The clinical and ethical importance of measuring consciousness: the case of sedation at the end of life

In the previous chapter, it was shown that there are reasons to believe that permanently taking away consciousness is not morally neutral. Many of the available guidelines on sedation seem to accept this and stress that consciousness should be reduced *proportionally* to the symptoms that a patient is suffering from (i.e. patients should not be sedated too lightly, but neither should they be sedated too deeply). Continuous sedation is portrayed as a proportionate response to severe symptoms.

In view of the importance of sedation proportionality, it is striking that so little evidence is available concerning the measurement of depth of sedation that is achieved in continuously sedated patients. One can only claim that a patient has been sedated to a correct level if this level has indeed been assessed. Currently, the most commonly used assessment technique is basic clinical judgement. The use of sedation scales, which provide a somewhat more objective way of assessing a patient's consciousness level, is sometimes suggested. Both clinical judgement and the use of sedation scales, however, also pose risks, as they reduce 'consciousness' to 'response to external stimuli', and from other research (e.g. as reported in anaesthesia literature) we know that patients who do not respond to stimuli can nevertheless still be conscious. One of the goals of continuous sedation, namely providing a distress-free and dignified end, can therefore not be said to be guaranteed for all.

Some other techniques do exist, such as EEG monitoring. The result of an EEG is highly complex and not easily interpretable by all physicians, but some EEG derivatives have potential. One of the promising techniques is a Bispectral Index monitor, which processes the EEG signal to yield a single number indicating the degree to which a patient is sedated. The usefulness of this technique for palliative care in general and sedation in particular is not yet settled, as there has been little research on this technique in palliative care patients. In view of the importance of proportionality and

the problems associated with the now most current assessment techniques, it seems highly advisable that more research be performed. One can only call sedation a proportionate response to symptoms if one is committed to measuring the depth of sedation in the most adequate and ethically feasible way.

Chapter 8: Factors that facilitate or constrain the use of continuous sedation at the end of life by physicians and nurses in Belgium: results from a focus group study

The previous chapters all involve the discussions of common portrayals of continuous sedation at the end of life. These portrayals encouraged us to refer back to physicians and nurses actually performing continuous sedation, to ask them how they *perceive* and *experience* sedation. We therefore conducted a focus group study in April 2010 to find out which factors increase the likelihood that, in a particular case, sedation would be used. The specific question for this study was:

> What, according to physicians and nurses in Belgium, can make it more or less likely that, in a certain situation, continuous sedation at the end of life would be used?

We held four focus groups: two with nurses only (n=4 & n=9), and two with physicians only (n=4 & n=4). We ensured that the participants had, at least once in their professional career, been involved in continuous sedation at the end of life and that they came from a balanced mix of settings (home-care, hospital and palliative care team/unit). In these focus groups, we asked the participants about their experiences with the practice and the situations in which they would consider their involvement in sedation to be, psychologically, more or less difficult. More information concerning the precise methodology can be found in chapter 8.

It turned out that the participants had clear views on which factors increased the likelihood that sedation would be used. A choice for sedation was facilitated if the patient had severe physical symptoms, had a short-life expectancy, made an explicit request for sedation, or had family members who could cope with the stress of watching a loved one during the period of sedation. At the same time, it was indicated that this 'paradigm case' occurs only rarely. Deviations from the paradigm case may occur if the physician is hesitant to discuss sedation with a patient, but may also occur when sedation proves to be too difficult for family members (who are said to sometimes pressure the medical practitioners to increase dosages and speed up the sedation).

In short, this chapter provides an interesting look at how continuous sedation is perceived and experienced by the people actually performing it. As such this chapter also raises several ethical issues.

Chapter 9: Similarities and differences between continuous sedation until death and euthanasia – professional caregivers' attitudes and experiences: a focus group study

As argued in many of the chapters in this dissertation, the practice of CS has been portrayed in many ways, mostly to make the practice distinct from euthanasia and physician-assisted suicide. Of course, the fact that CS can be distinguished from euthanasia and PAS, does not mean that this distinction is always clear for the physicians and nurses actually involved in CS. In the focus groups already reported on in the previous chapter, many of the participants discussed the issue of the similarities and dissimilarities between CS and euthanasia, even though we did not specifically ask any question relating to euthanasia. Since this proved to be a topic of great importance, it is reported on in this chapter.

Physicians and nurses were often very clear about the fact that they considered CS and euthanasia to be very different. The most important reported difference was that euthanasia is almost always explicitly requested, while explicit requests for sedation were said to be rare. Moreover, nurses claimed they were less often involved in decisions for CS. The final important difference lay in the intention with which the practice was performed. In euthanasia, there is an intention to kill while in sedation there is only an intention to relieve distress.

However, the participants considered there were some cases where the distinction between CS and euthanasia could get blurred, for example when there was a shift in intention, from relieving distress to shortening life, or when medication was increased disproportionally.

At first sight, the experience of physicians and nurses therefore accorded with the way sedation is portrayed in international literature and in existing guidelines, namely as being distinct from euthanasia. When the distinction was less clear to the patient and/or her relatives, it was deemed important to make the distinction between CS and euthanasia more clear in order to avoid confusion. However, it was at the same time suggested that the recommendations were not always followed and that in some cases it became difficult to see which was which. Medication *is* sometimes increased

disproportionally, and sometimes there *is* an intention to hasten death. These are important findings that need further exploring and ethical debate.

Chapter 10: Conclusions

This chapter summarises the most important findings of this dissertation and discusses some overarching conclusions. It also comments on the extent to which the different chapters have answered the research questions mentioned in this introductory chapter. After drawing some overarching conclusions, it will be argued that the more theoretical chapters and the more empirical chapters of this dissertation confirm and support each other.

Continuous sedation at the end of life is becoming a hot topic in the international literature, and many articles on CS are being published. I will therefore also explain what I believe this dissertation contributes to the debate in what respects this contribution is original.

In the final part of this dissertation, I will make some recommendations for future research on the one hand, and, on the other hand, for the future ethical debate concerning CS.

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Chapter 2
Defining continuous sedation at the end of life

As shown in the previous chapter, a lot of research has already been conducted which focuses on or covers continuous sedation at the end of life, and, as a result, a large amount of data is available. At the same time, the practice is the topic of considerable international ethical and legal debate. In the international literature, however, there is no generally accepted definition of what constitutes continuous sedation at the end of life, something which is clearly shown, for example, by Morita et al. (2001). Furthermore, many different concepts have been proposed to describe this practice and it is not always clear whether these concepts can be considered equivalent or what the precise differences between them are. This at least leaves open the possibility that authors who are seemingly debating the same thing, might have in mind practices that, although largely similar, differ in morally or conceptually relevant ways. I therefore consider it relevant to expand on the ways in which continuous sedation seems to be viewed and defined by different authors.[1] For the sake of clarity, I will also explain the concept and definition I will use throughout this doctoral dissertation.

2.1 Terminology

Concepts that have been proposed for referring to the practice of continuous sedation include: continuous (deep) sedation (e.g. Murray et al. 2008; Rietjens et al. 2008); sedation to unconsciousness in end-of-life care (e.g. Levine 2008); palliative sedation (e.g. Rousseau 2005; Materstvedt 2012); terminal sedation (e.g. van Delden 2007; Battin 2008); continuous palliative sedation (e.g. Van Deijck et al. 2010); and proportionate palliative sedation and palliative sedation to unconsciousness (e.g. Quill et al. 2009).

Not all of these concepts are used widely and the concept that seems to be used most frequently is 'palliative sedation', a term which, for several reasons, I will not use in my dissertation. Palliative sedation is often used broadly to refer to all types of sedation at

[1] Some authors are explicit in stating that they 'define' continuous sedation (or a synonym) in a certain way (Morita et al. 2002; Elsayem et al. 2009), however other authors use less specific language and, for example, explain what they believe continuous sedation 'refers to' (Cellarius 2008), 'is' (Davis 2009), or 'involves' (Hasselaar 2008). For the purposes of this dissertation I take all of these to be instances of definitions, as they are all ways in which the authors make clear what they mean when referring to CS. Though I am aware that what constitutes a definition, which types exist, and what the formal criteria for a proper definition are, are subject to theoretical debate (e.g. Robinson 1962), I shall make abstraction of this and use the concept in a broad way.

the end of life, including light and deep sedation, as well as continuous and intermittent sedation. In this dissertation I mainly focus on the particular type of sedation that is most controversial, and is therefore most open to ethical debate, namely sedation that is administered continuously until death occurs. Accordingly, I believe that it would only add to the existing confusion if a broad concept were used for this specific practice. Moreover, I consider the term 'palliative sedation' to be overly suggestive. In linguistics, this is known as 'semantic prosody', whereby a concept or word gains positive or negative meaning by juxtaposition with other words. Here 'sedation' gains a positive meaning by being combined with 'palliative'. Furthermore, by including the term 'palliative', the concept seems to impose its own justification as an acceptable part of medicine and palliative care. The suggestion then seems to be that in using this practice, physicians intend to palliate suffering rather than, for example, to shorten life. Though it may be true that sedation is a part of palliative care and is ethically acceptable, it seems improper to include elements of moral justification in a definition or in the concept itself. I am therefore in agreement with authors who have suggested that 'palliative sedation' runs the risk of being overly euphemistic (van Delden 2007).

'Terminal sedation', on the other hand, focuses on the end-point of sedation (i.e. the death of the patient) rather than on the presumed purpose of the process (the palliation of suffering). This concept has been criticised by some for suggesting that the practice has to do with 'terminating' life or that seeking death is an integral part of successful sedation (e.g. Morita et al. 2002). Yet others seem to prefer this concept because it is descriptive and merely stresses an essential element of sedation - that it is in fact an end-of-life decision (Materstvedt & Bosshard 2009; Den Hartogh 2006). Battin, for example, notes that:

> By avoiding the word "terminal" and hence any suggestion that death may be coming, the most important feature of this practice is obscured and terminal sedation is confused with "palliative care." (Battin 2008, 28)

It thus becomes clear that neither 'palliative sedation' nor 'terminal sedation' can really be considered to be a neutral term. This has been expressed elegantly by van Delden (2007):

> The preference for "terminal" seems to be held primarily by those who want to unmask this type of sedation as a form of euthanasia, assuming that by doing so its moral status is determined as well. Those who prefer "palliative" usually argue that this type of sedation is normal medical practice and that "terminal" would induce the false belief that it is not, for instance, because of the association with the word "termination" (van Delden 2007, 187)

In this respect it is interesting to note that, in a survey among German experts by Simon et al., it was shown that the term 'palliative sedation' was preferred mostly by people with a medical background, while experts without a medical background tended to prefer 'terminal sedation' (Simon et al. 2007). This might indicate that medical practitioners feel more comfortable using a terminology that implicitly suggests continuous sedation to be in line with the 'standard medical care' that they provide.

In this tug-of-war over which concept best describes the practice at hand, a third concept is sometimes proposed, namely 'continuous sedation at the end of life'. This concept has the advantage of being descriptive and, as such, particularly clear about which practices are meant to be covered; every sedation, regardless of depth, that is administered continuously until death follows. Probably due to its clarity and perceived neutrality, the term has been used in empirical research (e.g. Miccinesi et al. 2006; Seale 2010; Anquinet et al. 2012). I believe that this descriptive concept not only benefits the execution and interpretation of research, but could also benefit the ethical debate on sedation. Thereby, this concept will be used throughout this thesis.[2] Where necessary and relevant, I will also refer to a more specific and more controversial type of continuous sedation, namely continuous *deep* sedation (CDS), where patients are continuously sedated to a coma-like state.

2.2 Existing definitions

Just as there are many concepts, many definitions have been proposed for continuous sedation at the end of life. What all of these definitions of sedation share is that they stress that the practice has to do with patients experiencing a loss or reduction of consciousness until they die. Beyond this point of agreement, there is much debate. The various suggested definitions range in specificity, with some definitions being very general, and thus including many types of sedation, while others are specific and exclude many cases of consciousness loss at the end of life. In this section, I want to discuss some of the elements that can be found in currently proposed definitions of continuous sedation (CS) and that often serve to exclude certain cases. As definitions exclude more cases, the practices they define or determine become narrower.

[2] With the exception of cases, for example in chapters 8 and 9, where I quote other authors or focus group participants who use different concepts.

Distinguishing medically-induced from natural loss of consciousness

Studies have shown that diminished consciousness frequently occurs as part of the 'natural' process of dying,[3] meaning that part of the loss of consciousness at the end of life is not medically-induced (Fainsinger 1998). Hence there is a first distinction which is between medically-induced loss of consciousness and 'natural' loss of consciousness. These latter cases, as all definitions agree, are *not* in themselves considered to be cases of continuous sedation. The former, however, are, and some suggested definitions take *all* of the continuously medically-induced cases of reduced consciousness until death to be cases of 'continuous sedation'. For example, van Delden, defines what he calls terminal sedation as 'sedation until death follows' (van Delden 2007, 187).

It is to be noted, however, that the distinction between 'natural' and medically-induced loss of consciousness is far from always clear cut. Patients at the end of life often receive many kinds of medication – frequently with some sedative effects. Coupled with a 'natural' degeneration of consciousness at the end of life, it may often be unclear which causal role each of the drugs plays in reducing a patient's consciousness. Some studies indeed raise doubts regarding the contribution of sedatives to loss of consciousness, such as for example a study by Kohara et al. (2005) showing surprisingly little difference in consciousness levels between sedated and non-sedated patients.[4] In individual cases, it might not always be clear what precisely causes a lowering of consciousness. From an ethical point of view, one could argue that this may be of little relevance since the primary goal of end-of-life care is to reduce suffering in dying patients. This goal is achieved regardless of whether the reduction of consciousness can be attributed to medication that is administered, or simply to the dying process itself. Nevertheless, physicians should be able to judge the effect of the medications that they prescribe and if a medication is administered that does not achieve the effect it is given for, or even has no effect whatsoever, one could ask why this medication is given. Indeed if one is aiming at reducing suffering in the least invasive way possible, this should not include the administration of medication without any (significant) effect.

[3] The word 'natural' is used here in the strictly descriptive and not the moral sense of the word.

[4] Although it is unclear what constituted a non-sedated patient in this study and which kind of medications such a patient received.

Loss of consciousness as a side-effect or an intention

A general definition of sedation, such as the one given by van Delden, is uncommon, and most authors in their definitions of continuous sedation further distinguish intentionally sought, medically-induced diminishing of consciousness from cases where loss of consciousness is medically-induced, but is a side-effect of another treatment. Continuous sedation is then limited to the former cases. Simon et al., for example, conducted a survey among German medical ethics specialists, of whom '73% (...) would only speak of terminal sedation when sedation until death is intended' (Simon et al. 2007, 3). This can also be seen, for example, in the definition of sedation formulated by Tännsjö: 'a procedure where through heavy sedation a terminally ill patient is put into a state of coma, where the intention of the doctor is that the patient should stay comatose until he or she is dead' (Tännsjö 2004, 15).

Good examples of cases where loss of consciousness can be said to be a side-effect include those where analgesics (such as for example morphine) are given to reduce pain but cause drowsiness. This sedative side-effect is not aimed at and can sometimes be considered to be unwanted by medical practitioners or by patients wanting to be as conscious as possible for as long as possible. This idea was put forward, for example, by hospice physician Dr Heyse-Moore who, in correspondence to *Palliative Medicine,* stated:

> We try to avoid sedating patients where possible. Patients don't usually like it, nor do their relatives. Preservation of consciousness is rightly seen as an important priority. (Heyse-Moore 2003, 469)

Classic examples of cases where loss of consciousness *can* be said to be the intention include cases where sedatives (such as midazolam or levomepromazine) or anaesthetics (such as propofol) are administered with the aim of reducing consciousness. These drugs have a sedative effect as a *primary* effect and, so it is argued, can therefore only be used with an intention of lowering consciousness.

However, distinguishing intentional sedation from sedation as a side-effect is often extremely difficult or even impossible, since (1) there is no absolutely reliable way of knowing the intentions of others; and (2) there need not be only a single intention.

First, regarding the ways to indentify a person's intention. The intention one has in acting in a certain way is highly personal as it is, according to a standard account of intention (Anscombe 1958), the answer to the question: 'why did you act in the way that you did?'. According to this influential interpretation of intention, continuous sedation would include all cases where the answer to the question 'why did you administer these

medications?', is something in the form of 'to reduce that patient's consciousness'. The problem here is that there is no way to check whether a respondent answers the 'why?' question truthfully, so we are unable to check her self-proclaimed intention. One could attempt to resolve this by looking at the type of drug and/or the dosage used, and by linking this to the claimed intention. Indeed, if a physician claims to have had the intention to relieve pain (thereby reducing consciousness as little as possible), one would expect to have this confirmed by the type and dose of the medications that are administered, but many difficulties continue to exist.

As regards the type of drug, it is true that analgesics have easing pain as a primary effect, whereas hypnotics have a reduction of consciousness as their primary effect. Nevertheless, the type of medication used does not *necessarily* identify the physician's intention in using that type of medication. Studies from The Netherlands (Rietjens et al. 2008) and Flanders (Belgium) (Chambaere et al. 2010) show that, in many cases, opioids and other analgesics *are* in fact deliberately used for their sedative (side-)effect. The Belgian research even suggests that the number of sedation cases in which only opioids are used as a means to induce consciousness loss was as high as 31% in 2007. The Netherlands equally has a high number of cases in which only opioids are used, although this number is claimed to have dropped after the introduction of a Dutch national guideline on sedation, encouraging the use of benzodiazepines rather than opioids (Hasselaar et al. 2009). Furthermore, another study conducted in The Netherlands showed that the use of opioids is not unrelated to continuous sedation, in the sense that '[t]he dose of opioids used at various time points between admission and death was strongly correlated to the probability of [continuous sedation]' (Oosten et al. 2011, 2341). The use of analgesics does not therefore necessarily rule out an intention to sedate. Just as the use of analgesics does not rule out an intention to sedate, the use of sedative drugs does not *imply* an intention (only) to sedate. Within the category of sedatives one could distinguish between tranquilizers and hypnotics, something which is discussed in an interesting way by Heyse-Moore (2003). Drugs used for tranquilizing have the aim of calming a patient in distress but, like some analgesics, also have a sedative effect. The degree to which tranquilizers sedate depends on the type of drug; haloperidol is a tranquilizer with little sedative potential, while levomepromazine has a substantially higher sedative effect. For these types of drugs, a case could perhaps be made that, like analgesics, the primary goal of their use is not always to sedate but to calm, even though a reduction of consciousness necessarily accompanies their use. Some tranquilizers, one could claim, may even heighten awareness since a patient, who is relieved from distress so grave that it leaves her unable to think of anything else, may be able to reason and reflect more clear-headedly. Hypnotic drugs, such as midazolam, have a strong sedative effect and reduction of consciousness is their primary function. However, some of these hypnotic drugs, such as for example midazolam, are sometimes

given in low dosages for their tranquilizing properties. Linking the type of drug used to the intention behind its use is therefore inherently problematic, and looking at the dosages at which these drugs are used might indeed be more enlightening.

Cases where hypnotic drugs such as midazolam are continuously given to a patient in sufficiently high doses could then be said to be clear examples of intentional continuous sedation in view of the medication and dosage used. However, though there might be clear cases where intention cannot be denied in view of the facts, a large grey area continues to exist. What constitutes a high dose might often be physician-dependent; what one physician considers a normal dose of medication, might be considered a high dose by another physician. Huge differences also exist between patients, and what constitutes a high dose for one patient (e.g. a midazolam naïve patient), might be a low dose for another patient (e.g. a patient that has been on midazolam for a long time). Numerous other factors influence drug dose, for example age, physical condition, body-weight, etc. What constitutes a 'high dose' can not therefore be put into absolute numbers, but can only be assessed if all relevant aspects of the individual case are known.

As was argued above, linking intention to the type of drug and dosage used is often difficult, but it is not even clear whether they should be linked at all. When physicians intentionally administer medication, they prescribe what they *believe* to be the right type of drug and the right dose, although they need not be correct in their belief. This nuance is far from trivial as it makes clear that physicians might mistakenly under- or overestimate the effect of the medications they prescribe. For example, a physician might have the intention to render the patient unconsciousness and indeed *believe* that she is doing so, whilst in reality the dose of medication she uses is unlikely to actually cause unconsciousness. In this case it would be wrong to conclude from the fact that a low dose of medication was given that the physician did not have the intention to sedate. The reverse can also occur, as a physician might *believe* that she is administering the lowest dose possible, while in fact she is administering a higher dose than is necessary to achieve her intended effect. In this case, a high dose need not imply an intention to sedate.[5] Thus, for example, when research from Flanders (Belgium) shows that physicians sometimes had an intention to shorten life (Chambaere et al. 2010), this does not *necessarily* mean that life was actually shortened.

[5] Which is not to say, of course, that the physician is not responsible in this case. If a physician administers medication in overly high dosages and should have known that a lower dose was appropriate, this is a medical error and possibly medical malpractice. This, however, does not change the fact that in such a case there was no intention to sedate.

Some authors argue that, even if intention could and should be inferred from the type of drug used or the dosage in which it is used, assuming a single and clear intention is an oversimplification of what it means to take concrete clinical decisions (Quill 1998). It may often be difficult to specify precisely what the main intention of an action is, and to differentiate between intentions, co-intentions, and much welcomed side-effects.

Indications for sedation

Although, as was shown above, limiting continuous sedation to only those cases where the loss of consciousness is intended carries many problems, some authors specify even more and include the reason why sedation is (or should be) given in their definition. In some definitions this reason is stated in general terms. Thus, the definition used by Davis (2009), for example, focuses on the relief of symptoms:

> Palliative sedation is the intentional induction of loss of consciousness for the purpose of symptom relief. (Davis 2009, 875)

Other definitions specify that the aim of sedation is to relieve distress (e.g. Gevers 2003). Symptom and distress relief are, of course, quite general concepts, and many other definitions specify that sedation must concern the relief of intractable or refractory symptoms. An example of a definition on this level of specificity is the one used in an often quoted article by de Graeff and Dean:

> Palliative sedation therapy (PST) is the use of specific sedative medications to relieve intolerable suffering from refractory symptoms by a reduction in patient consciousness (de Graeff & Dean 2007, 68)

This mentioning of refractory or intractable suffering in the definition of sedation is common (see for example Morita et al. 2002; Kohara et al. 2005; Oosten et al. 2011). One could contrast this with cases where the administration of sedatives and the subsequent loss of consciousness are used as a means to hasten death, a practice that is often referred to as 'slow euthanasia', after an influential article by Billings and Block (1996). Indeed, the very purpose of including the aim of continuous sedation in its definition often seems to be to highlight the difference between sedation and euthanasia. See for example the definition of sedation as proposed by Rousseau, where the difference with euthanasia is made explicit:

> PS [palliative sedation] can be defined objectively as the intention of purposely inducing and maintaining a sedated state, *but not deliberately causing death*, in

> specific clinical circumstances complicated by refractory symptoms (Rousseau 2000, 1064, emphasis added)

The same idea seems to lie behind a similar distinction, sometimes made in definitions of sedation, between proportional and disproportional sedation (e.g. Quill 2009). Such authors limit the concept of sedation to cover only those cases where sedation is administered proportionally, meaning that the dosage of sedatives is proportional to the severity of the symptom causing distress and that there is no shortening of life.

Including the indication for sedation in one's definition also brings with it some of the problems associated with distinguishing intentional from accidental sedation discussed in the previous section. The reason a physician administers a sedative drug can never be truly ascertained. What, arguably, could be somewhat more objectively ascertained is the presence of distressing or refractory symptoms (and even the refractory nature of symptoms is sometimes claimed to be a subjective matter). However, most definitions do not talk about sedation in patients *with* refractory symptoms, but rather about lowering of consciousness *for the relief of* refractory symptoms. Accordingly, the symptoms need to be present, and they have to provide the reason sedation is initiated. To be certain whether they form the actual reason, one would have to gain access to a physician's intention, which, as I argued in the previous section, is difficult, if not impossible.

Patient's life expectancy

Many definitions also include the limitation that sedation is used for terminally ill patients, or in patients' last days of life. The American Medical Association, for example, uses the following definition:

> Palliative sedation to unconsciousness is the administration of sedative medication to the point of unconsciousness in a terminally ill patient. (Levine 2008)

Not only is this a recommendation that is made in many guidelines, it is also not uncommon in many definitions (Chater et al. 1998; Cellarius 2008). The Dutch national guideline on palliative sedation also limits sedation to those cases where it is administered in 'the last phase of life' (KNMG 2009).

The reason here, as with the previous criterion of exclusion, seems to be to highlight the difference between sedation and euthanasia. By using sedation only in dying patients, it

becomes unlikely that life is shortened, thereby making the practice less problematic. This has led Cellarius to claim that terminal sedation, as he calls it, should be clearly distinguished from what he calls Early Terminal Sedation (ETS) (i.e. sedation administered to patients who are not imminently dying) since that is 'a distinct entity and should be treated clinically, ethically and legally as such' (Cellarius 2011: 47).

Other criteria of exclusion

As argued above, some definitions are very specific about which kind of practice they cover. Besides the elements discussed above, some definitions include even more specific requirements (although these are less common). For example, some definitions include as sedation only those cases where the sedation is *deep*. Examples include the definition given by Tännsjö (2004), who talks about inducing a coma, and research by Inghelbrecht and colleagues who talk only about continuous deep sedation, which they define as: 'the administration of drugs to keep the patient in deep sedation or coma until death' (Inghelbrecht et al. 2011, 871).

On a few occasions, authors draft their definitions in such a way as to exclude cases where artificial hydration and nutrition are given. Kuhse, for example, states:

> I understand 'terminal sedation' as the deliberate induction and maintenance of deep unconsciousness in a terminally or incurably ill patient until death occurs, coupled with the forgoing of medical treatment, and the withholding of hydration and nutrition. (Kuhse 2004, 58)

2.3 The definition of sedation used in this dissertation

The previous section provided an overview, with some critical reflection, of some of the elements one can commonly find in the various definitions of sedation that are used in the literature. Moving on from this overview, I now want to clarify what I shall adopt as the definition of continuous sedation. My definition is: *continuous sedation is the practice whereby one administers sedative drugs resulting in the continuous reduction or taking away of a patient's consciousness until death follows.*

With the previous discussion of the differences between the currently existing definitions in mind, certain aspects of my definition need to be stressed.

First, it is clear that I only discuss sedation at the end of life that is administered *continuously*, meaning that a patient is continuously in a state of reduced consciousness.[6] Undoubtedly, *intermittent* sedation can and does occur and can be a valuable tool to relieve suffering at the end of life, but it is not the topic of this doctoral dissertation. This is not to say that intermittent sedation is morally unproblematic, but merely that the practice raises issues that are quite different from those raised in continuous sedation, and discussing it would merit a dissertation of its own.

Moreover, the fact that sedation is administered continuously does not mean that the level of sedation is necessarily constant. Rather, the extent to which a patient is conscious can vary significantly over the time she is sedated. This is also central to my definition which specifies a *reduction or taking away of a patient's consciousness*, meaning that both deep and light sedation are captured. More will be said about this when I distinguish between different types of sedation.

A third important aspect of my definition is that, while it limits sedation to those cases where sedative drugs are administered, it makes no assumptions regarding the *intention* with which sedation is brought about. There are many sedative drugs and, as argued above, their use cannot readily be linked to a certain intention. Furthermore, the definition I propose deals with all cases where the administration of sedative drugs *results in* a reduction or total loss of consciousness. This goes beyond those cases where drugs are administered *in order to* sedate and to include cases where loss of consciousness is a side-effect. The reason for this aspect of my definition is that, as argued above, distinguishing intentional from non-intentional sedation is often highly problematic. Furthermore, the intention with which sedation is performed should be an element in the ethical debate surrounding continuous sedation, and therefore should not be included in the definition.

Not only does my definition not contain assumptions regarding intention but, unlike many of the existing definitions discussed above, it contains very few exclusive elements. My definition does not limit CS to practices used only with certain types of patients (e.g. terminally ill patients) or in response to specific indications (e.g. for the relief of intractable suffering or refractory symptoms). My proposed definition includes

[6] It should be noted that this definition does not refer to the practical way in which sedation is administered to a patient. Although it is the case that continuous sedation is usually performed by way of continuous administration of a sedative (intravenously or subcutaneously), the intermittent administration of single shots of sedatives at regular intervals in order to maintain a certain degree of sedation would also constitute continuous sedation according to my definition.

three readily determined elements – sedation is given, it is given continuously, and it is given until death. The definition is thus one that is as descriptive as possible because I agree with other authors that the conditions that would make the practice morally acceptable or not should be discussed in ethical debates and not included in the definition (van Delden 2007). Examples of definitions that include normative elements have been given above. A counter-example that I do want to discuss, is the definition given by the European Association for Palliative Care in its recommended framework for the use of sedation. That recommendation states:

> [t]herapeutic (or palliative) sedation in the context of palliative medicine is the monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden of otherwise intractable suffering in a manner that is ethically acceptable to the patient, family and health-care providers. (Cherny et al. 2009, 581)

This, like the 'standard view' discussed in chapter 1, is tautologous – acceptable sedation is acceptable. Not only does this definition include several criteria of due care, such as the reason for inducing sedation (i.e. intractable suffering), it states that for any case to be a case of continuous sedation (or palliative sedation as the EAPC calls it) it *by definition* needs to be ethically acceptable to everyone involved.

The problem in defining sedation in a way that includes normative elements has been touched upon in the previous chapter, namely that it makes proper ethical analysis impossible. For example, an argument showing that the use of continuous sedation is (or is not) ethically unproblematic is futile if one defines sedation in such a way that all potentially problematic cases do not count as cases of sedation. In a similar vein, research showing that sedation does not shorten life is problematic if the definition one uses only covers cases where there was no intention to shorten life and the patients were imminently dying. Available research, discussed earlier, indicates that there are in fact large differences in how physicians perform continuous sedation, i.e. that in practice the term covers cases beyond the morally unproblematic ones that some definitions would only have discussion limited to. It has, for example, been shown that in Flanders (Belgium) continuous deep sedation is sometimes performed with an intention to hasten death. To simply exclude these cases from being considered as cases of continuous sedation is, in my opinion, both wrong and misleading. While such ethically problematic cases may not fit into a sanitised picture of 'palliative sedation', they are definitely cases of sedation, and I therefore defend a broad definition of the term continuous sedation.

2.4 Why use a broad definition?

I have argued that it is incorrect, if not blinkered, to use a narrow definition of sedation as problematic cases are then excluded. One might retort and say that there are also problems in using a broad definition. A broad and inclusive definition can also be used as a sanitizing technique, not by excluding problematic cases, but by having one's definition include *more* unproblematic cases than would be covered by a narrow definition. This could be used to draw attention away from the fact that, regardless of how many unproblematic cases of sedation there are, at least some problematic cases provide reasons for an ethical reflection. For example, having a broad definition might cause the incidence of cases in which life was shortened, or in which there was an intention to hasten death, to be lowered, allowing one to claim that life-shortening *rarely* occurs in sedation or that an intention to kill is *uncommon*. In short, by including many unproblematic cases one could aim to transfer the unproblematical nature of these cases to continuous sedation as a whole.

To this I would reply that, while a broad definition may indeed run the risk of lumping together both problematic and unproblematic practices, the problem lies not in the fact that the definition is broad, but instead in the fact that the definition is deliberately used as a tool to skew an ethical analysis. This does not plead against broad definitions, but only against drafting such definitions in such a way as to support the moral conclusion one wants to arrive at.

In this dissertation, I make a plea for a definition that is *truly* descriptive, that merely identifies which practices are up for debate. Of course, within the included cases, it remains important to distinguish between types of sedation which differ in moral respects. Moral evaluation should therefore take place with respect to each such type of sedation. Some moral issues are present in many such types, while others are unique to one specific type of sedation. This will be discussed below.

2.5 Types of sedation

As mentioned above, it is highly important for a nuanced ethical debate to identify different types of sedation. I see three key reasons for this. First, continuous sedation can be administered with various degrees of consciousness loss as a result. The overall consensus on continuous sedation is that it should be administered proportionally to

the severity of a patient's symptoms. Symptoms which cause a lower degree of suffering will therefore permit a patient to be more lightly sedated, while more severe symptoms might require a more drastic form of continuous sedation, namely continuous *deep* sedation where a patient is sedated to a coma-like state and is said to have no experiences any more: neither negative nor positive experiences. It is clear that it is the latter type of sedation that is most controversial and therefore most in need of ethical debate. Lighter continuous sedation lowers consciousness, but potentially only to a level at which the patient is still capable of communicating. The patient may then still be able to communicate her experiences and suffering, making it easier for physicians to adjust the sedatives proportionally to the symptoms. Deep sedation is necessarily accompanied by a loss of all ability to communicate. Assessing whether sedation is too deep (i.e. the patient is sedated more heavily than necessary) or too shallow (i.e. the patient is still experiencing suffering) then becomes difficult because one can only rely on observers' assessments. Finding the right level of sedation is, nevertheless, extremely important since bringing somebody into a state in which she is still experiencing suffering, but is no longer able to communicate about it, would clearly be undesirable and ethically unacceptable. This issue of proportionality is further analysed in chapter 7.

Second, like most other medical practices, continuous sedation can be administered voluntarily (i.e. with request or consent), non-voluntarily (i.e. in a patient who was unable to give consent), and involuntarily (i.e. without asking a nevertheless competent patient or even explicitly against that patient's request).[7] The few guidelines that exist share the recommendation that sedation be administered voluntarily when at all possible, and otherwise with proxy consent. From an ethical point of view, this indeed seems acceptable. Research from Belgium, quoted earlier, indicates that sedation on request is not the most common type of sedation, but rather that this is non-voluntary or involuntary sedation. This is not necessarily problematic since existing guidelines stress that, unlike in euthanasia, a request or consent for CS is not always possible or even necessary. Research from The Netherlands indeed indicates that, in a high number of cases, patients were incompetent when continuous sedation was considered (Rietjens et al. 2004). This could partly be due to the fact that continuous sedation can only be considered for patients with a short life expectancy and precisely these patients are more likely than other patients to have become less competent or even incompetent. This of course does not tell the whole story. That a patient is incompetent the moment

[7]Not all practices can be performed non-voluntarily or involuntarily. Notable exceptions are physician-assisted suicide and euthanasia, which, as it is defined in The Netherlands and Belgium, can only occur voluntarily since there 'euthanasia' refers only to life-shortening by a physician at the explicit request of the patient, i.e. only voluntary euthanasia can be legal.

sedation is considered, does not necessarily mean that continuous sedation could not have been discussed with the patient in an earlier stage. Many terminally ill patients have symptoms that become worse as their disease progresses, so for these patients a future need for continuous sedation is possible or even likely. There are also plenty of reasons for discussing sedation before it becomes indicated or necessary since, as already discussed, many patients lose consciousness at the end of life. So one cannot claim that it is generally unexpected that patients would become incompetent at the time when continuous sedation is needed to relieve distressing symptoms. Moreover, it is known that physicians are not perfect at giving precise estimates of life expectancy (e.g. Wilson 2005; Clarke et al. 2009), so it is quite possible that many patients may need continuous sedation sooner than their physicians had predicted. Perhaps continuous sedation should be included in the package of end-of-life care information one gives to terminal patients.

A more difficult question is whether there may be reasons for initiating sedation involuntary. As regards deep sedation, this is a far reaching procedure that completely removes the patient's ability to have any experiences at all. Coupled with the fact that autonomy is sometimes cited as a ground for justifying the practice, it is unclear how involuntary continuous deep sedation could be considered ethical. Sedation to a lower level of unconsciousness is less far-reaching, but as autonomy is also invoked to justify this practice, it is difficult to see how one could continuously sedate a competent person against their will. Research from Rietjens et al. (2004) gives insight into the reasons why continuous sedation was not discussed, and in a small number of cases (7%) the reason given was that 'deep sedation was clearly in the best interest of the patient' (Rietjens et al. 2004, 181). I believe that this paternalistic justification is highly questionable with a competent patient and that it is hard to see how it could be a valid reason for not discussing a practice as far-reaching continuous sedation.

A third reason why it is important to distinguish between different types of sedation relates to the difference between continuous sedation with administration of artificial nutrition and hydration (ANH) and continuous sedation where ANH is withheld. Some question whether we should see continuous sedation *without* administration of ANH as a proper practice, and argue that the administration of ANH is distinct from continuous sedation (Cellarius 2011). Nevertheless, in everyday practice the withholding of food and fluids often accompanies sedation. Research indicates that in Flanders (Belgium) in 2007 it was withheld or withdrawn in 57% of cases (Chambaere et al. 2010). Moreover, when ANH is withheld it seems to change some aspects of continuous sedation, for example by setting a time limit on sedation, since no one can survive for weeks on end without intake of fluids. The absence of nutrition and hydration also makes life-shortening more likely than were food and fluids to be given. It is clear that concerns

regarding CS and life-shortening therefore often pertain to sedation without ANH. In this respect it is interesting to refer back to the research by Rietjens et al. (2004), which looked at deep sedation combined with a decision to withhold or withdraw ANH. When it came to the decision to forego nutrition and hydration, this was requested by the patient *in only 9% of cases*, and was discussed with the patient *in only 34%*. In view of the drastic nature of the decision, it is surprising that consent or a request was present in so few cases. Unfortunately, this study gave no indication as to what could be the reasons for not discussing this decision with the patient.

To conclude, my proposed definition of continuous sedation at the end of life is: continuous sedation is the practice whereby one administers sedative drugs resulting in the continuous reduction or taking away of a patient's consciousness until death follows. As argued above, this is a rather broad definition and captures many different types of CS. Though these different types carry the same label, it is clear that they should be clearly distinguished as they differ in ethically relevant ways. For example, continuous deep sedation without ANH raises other ethical issues than continuous light sedation with ANH does. Nevertheless, I believe a broad definition to be perfectly combatible with a nuanced view on the various ways in which CS can be administered.

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Chapter 3
Introducing continuous sedation at the end of life

Forthcoming as book chapter:

Sterckx, S., **Raus, K.** and Mortier, F. (2013) "Introduction", Chapter 1 in: Sterckx, S., Raus, K. & Mortier, F. (eds) "*Continuous sedation at the end of life – Clinical, legal and ethical perspectives*", Cambridge: Cambridge University Press. (Under contract for the 'Bioethics and Law' series of Cambridge University Press, to be published fall 2013)

3.1 The language of human suffering

Most people's conception of what constitutes a good death is something like the following: at an advanced age, one falls asleep peacefully in one's bed, preferably at home, more or less free from pain, if possible surrounded by one's relatives and close friends, accepting the fact that death is inevitable, in a clear state of mind, after having had the opportunity to balance one's life and to prepare thoroughly for the long goodbye, all in all satisfied with the life one has led, and while regretting some of the mistakes one has committed, hoping to leave behind a positive reputation.

Unfortunately, although palliative care and palliative medicine appear to be committed to this picture of a good death, and, through the benefits of pharmacology and proper care, do contribute a lot to bringing dying patients closer to that ideal, in many cases dying remains a hard and ugly thing. The classic (fictionalized) expression of this harsh reality is, of course, The Death of Ivan Ilych (1886) by Leo Tolstoy. At one point he describes Ivan Ilych's predicament as follows:

> From that moment the screaming began that continued for three days, and was so terrible that one could not hear it through two closed doors without horror. At the moment he answered his wife realized that he was lost, that there was no return, that the end had come, the very end, and his doubts were still unsolved and remained doubts. "Oh! Oh! Oh!" he cried in various intonations. He had begun by screaming "I won't!" and continued screaming on the letter "O". For three whole days, during which time did not exist for him, he struggled in that black sack into which he was being thrust by an invisible, resistless force. He struggled as a man condemned to death struggles in the hands of the executioner, knowing that he cannot save himself. And every moment he felt that despite all his efforts he was drawing nearer and nearer to what terrified him. He felt that his agony was due to his being thrust into that black hole and still more to his not being able to get right into it. He was hindered from getting into it by his conviction that his life had been a good one. That very justification of his life held him fast and prevented his moving forward, and it caused him most torment of all. (Tolstoy 1886, 12)

We have left out Tolstoy's evocation of the physical torments Ivan Ilych went through, and instead focused on part of the description of Ivan's existential suffering. For

Tolstoy, the description fits into the picture he draws of a man who during his lifetime has failed to address the inescapable fact that he had to die.

In the medical context, however, as well as in the medical-professional literature, the features of Ivan's suffering to which Tolstoy draws our attention, are termed 'symptoms'. 'Symptoms of what?', one may ask. Lack of reflection, unlike pain caused by cancer, cannot plausibly be conceptualized as a 'symptom' of an underlying disease. Yet this is how modern medicine, and more particularly palliative medicine, has to translate part of the distress of today's Ivan Ilyches. We would submit that the 'symptoms' that palliative medicine seeks to alleviate or eliminate are in fact not defined in a strictly medical way, but rather in a *normative* way, i.e. starting from a particular conception of what a 'good death' implies. Indeed, what counts as a 'symptom' for palliative medicine, is a deviation from our culturally ingrained conception of what constitutes a 'good death'.

To be clear, we do not believe there is something inherently wrong with this. The tasks of contemporary medicine clearly go beyond the curing of diseases and in many ways incorporate normative ideals (e.g. preventative medicine, aesthetic surgery, etc.). However, we do believe it is important to remember that palliative medicine and palliative care are *also* guided by normative ideals. Yet the way in which they process those moral values is inevitably coloured by a medical viewpoint, by a language that makes human suffering accessible to medical procedures and treatments.

In the context of today's palliative medicine, Ivan Ilych's existential suffering would be seen as a set of 'refractory symptoms'. In Tolstoy's view, this would be absurd, since the only person who might have lessened Ivan's terminal suffering, was Ivan himself, at a moment earlier in his life when he was still capable of choosing a life of reflection instead of a life of base self-contentment.

For contemporary medicine, then, the problem of the Ivans presents itself roughly as follows: although medication may help many or most of the dying to achieve a state of relative painlessness or serenity, sometimes very distressing symptoms do not respond (quickly enough) to any treatment. Even high and correctly administered doses of pain medication may not sufficiently control excruciating pain. Other symptoms may threaten to render a good death practically unattainable: uncontrollable seizures, severe nausea and frequent vomiting, lasting anxiety and disturbing hallucinations, continuing breathlessness, and so on. In the medical literature, such symptoms are labelled 'refractory'. They cannot be treated by the available medical means within a sufficiently short time span to make what remains of life bearable to the patient and/or

her environment. And of course making the end of life bearable is exactly what palliative care is devoted to.

On the internet, many stories of terminal illness can be found that illustrate how personal biography at the end of life gets interwoven with medical intervention. One of these is Serge's story, whose struggle with illness took about four and a half years.[1] It would take too much space to reproduce the 'case' of Serge. Suffice it to say that in 2004 Serge suffered a 'grand mal' (type of epilepsy) seizure that was caused by a frontal brain lesion and by lung lesions which were treated by craniotomy and chemotherapy. In 2007 a switch was made from curative treatment to comfort care. The palliative phase eventually lasted one and a half years. In the course of that period, Serge experienced severe seizures, deliria, extreme headaches, and so on, that were controlled in highly complex ways by medication and controlled sedation, until, a few days before dying, he stopped eating and in his very last days he died under continuous sedation.

This dissertation is about continuous sedation at the end of life. It is absolutely certain that, without the benefits of this end of life practice, Serge would have died a horrible death. That he was able to say the long goodbye to his loved ones, that he got the time and opportunity to reconcile himself with both life and death, that he did not have to go through excruciating pain, all this and more was only possible thanks to the use of palliative care techniques, of which continuous sedation until death was the ultimate one. Palliative care allowed Serge a good death, or at least one as good and as dignified as possible under the circumstances.

3.2 Continuous sedation at the end of life: consensus and criticism

There seems to be some degree of consensus that continuous sedation at the end of life is an ethically acceptable way to relieve otherwise intractable suffering, although reducing or even completely taking away a patient's consciousness is a far-reaching procedure, which reduces not only the experience of suffering, but *all* experiences. The results of a study by Simon et al. illustrate this consensus. In this study, 477 members of the German Academy for Ethics in Medicine were asked about their opinions regarding

[1] See http://www.docstoc.com/docs/72215262/Palliative_Sedation_2

continuous sedation. Ninety-eight percent of them 'regarded terminal sedation in dying patients with treatment-refractory physical symptoms as acceptable' (Simon et al. 2007, 1). Moreover, some of the currently used sedation guidelines state that the practice is ethically acceptable (American Medical Association 2008) and is to be considered as 'normal medical practice' (KNMG 2009).

However, continuous sedation until death has recently become subject to criticism, for various reasons. One reason has to do with the increase of its frequency: dying after having been continuously sedated for some time is quickly becoming one of the standard ways of dying.

Most people now die expectedly, after some medical decision has been taken that might influence the exact moment of death. Moreover, the trajectories that most patients follow until death call for the alleviation of distressing symptoms. For example, research from Belgium indicates that in Flanders (the Dutch speaking region of Belgium) in 2007, only 31.9% of all deaths were sudden (Bilsen et al. 2009). This implies that more than two thirds of all people dying that year had a longer dying trajectory, which was somehow medically assisted, first with a curative approach and later on - probably and hopefully – by means of comfort care. Medical care at the end of life also includes, as a standard component, the making of decisions that may shorten survival. A recent study in The Netherlands, for example, showed that in 2010, an end of life decision[2] was taken in 57.8% of all deaths (Onwuteaka-Philipsen et al. 2012).

There is thus reason to believe that a great need exists for effective medical interventions at the end of life. For example, Fainsinger et al. studied four palliative care programmes (in Israel, Durban, Cape Town and Madrid), showing that of all the palliative care patients in the in-patient setting, more than 90% required symptom control or management (Fainsinger et al. 2000). Although this study looked only at patients in a palliative care unit – who perhaps had a greater likelihood of experiencing severe suffering – it nevertheless indicates that the need for good symptom control remains overwhelming. This need is becoming more widely acknowledged and has led many commentators to conclude that being free from pain is nothing less than a fundamental right. As philosopher Margaret Sommerville phrases it:

> Leaving people in pain is both a human tragedy and a breach of the most fundamental concepts of human rights and human ethics. (Somerville 2001, 33)

[2] Understood here as a medical decision (i.e. a decision by a physician or a nurse) that affects or is believed to affect the timing of death of the patient and/or the possibility of meaningful experiences by the patient.

Somerville further argues that leaving people in pain 'should be treated as legally actionable medical malpractice' (Somerville 2001, 33), and this too is increasingly being recognised. In Belgium, for example, the 2002 Act on Palliative Care has made access to palliative care a legal right for every patient who requests it. Advances in palliative care and pain management have indeed made a pain-free end of life an achievable aim for many patients. In some cases, however, a patient's suffering is so severe that 'standard' palliative care is no longer able to relieve the suffering, leading physicians to make more far-reaching decisions, such as increasing medication to a potentially life-shortening dosage and, in countries where this is legal, carrying out euthanasia or physician-assisted suicide.

The end of life practice that is the focus of this book is the administration of sedatives resulting in the reduction or removal of a patient's consciousness, thereby ensuring that she no longer experiences any suffering. This is one option (often the only one available that is legally allowed) when suffering at the end of life becomes very severe and symptoms are no longer responsive to standard pain management.

We will come back to epidemiological findings on the frequency of continuous sedation until death. But apart from its sheer frequency, the practice raises ethical, clinical, and legal questions (see, for example Gillick 2004; Tännsjö 2004b). Many of these issues lie at the very heart of continuous sedation, such as, for example, the way in which this practice should be labelled and defined. Some commentators question whether continuous sedation is a proper end of life practice within the context of palliative care or whether it is instead just a specific type of euthanasia, a so-called 'slow euthanasia' (Billings & Block 1996). Furthermore, not only the ethical acceptability of continuous sedation at the end of life is under discussion, so too is its legality (see, for example, Gevers 2003).

In the absence of a single framework or procedure, there is no widely agreed upon way to perform continuous sedation at the end of life. Research has shown that considerable differences exist *between* countries, for example between Belgium, The Netherlands and the UK (Anquinet et al. 2012), as well as *within* the same country (e.g. Chambaere et al. 2010; Seale 2010). This shows that although there might appear to be some degree of consensus, there is hardly any single aspect of continuous sedation at the end of life that is not up for debate (see chapter 2).

3.3 Defining sedation at the end of life

There is no consensus on a definition of sedation at the end of life, and not even on a term to refer to the practice. Terms that have been proposed include: continuous (deep) sedation (e.g. Murray et al. 2008; Rietjens et al. 2008a), sedation to unconsciousness in end of- life care (American Medical Association 2008), palliative sedation (e.g. Rousseau 2005; Materstvedt 2012), terminal sedation (e.g. van Delden 2007; Battin 2008), proportionate palliative sedation versus palliative sedation to unconsciousness (Quill et al. 2009), etc.

The terminological issue is closely related to the definition issue, which in turn is closely related to the ethical and normative issues. As for a definition, various propositions have been made in the literature (Morita et al. 2001; de Graeff & Dean 2007; Cherny & Radbruch 2009), but currently no consensus exists on any of the proposed definitions. Nor is it likely that a consensus will ever evolve. The expression 'continuous sedation until death' covers different and yet closely related clinical practices and realities. Some of these practices are ethically contested. An example is inducing a continuous coma, say about four weeks prior to death, in a patient who requested a life-shortening intervention from her physician, who complied by taking away artificial nutrition and hydration (ANH). This patient is likely to die from dehydration and starvation rather than from the underlying disease she is suffering from. Let us call this the Slow Euthanasia Case (SEC). Under a broad 'descriptive' definition (i.e. one only taking into account whether or not the patient was sedated until death), SEC would be a genuine instance of 'continuous sedation until death'.

As van Delden argues (van Delden 2007; van Delden 2013 *forthcoming*), a definition of an end of life practice should be neutral, and whether the practice was ethically justifiable in a given set of circumstances should be evaluated separately. Others, however, might not be prepared to consider SEC as an instance of whatever their preferred expression for continuous sedation until death is (palliative sedation, controlled sedation, etc.). de Graeff & Dean, for example, state that: '[p]alliative sedation therapy (PST) is the use of specific sedative medications to relieve intolerable suffering from refractory symptoms by a reduction in patient consciousness' (de Graeff & Dean 2007, 68). This definition adds a descriptive qualifier ('to relieve intolerable suffering from refractory symptoms') which happens to play a major role in judging the ethical justifiability of continuous sedation at the end of life (labelled 'palliative sedation' by de Graeff and Dean and many others). It is clear that whether or not the intention of the physician was to relieve refractory symptoms, is ultimately an empirical question. Yet, by including this

particular requirement in the very definition of the practice, other types of continuous sedation (e.g. for non-refractory symptoms) are excluded.

The ethical issues are further obfuscated when, as is bound to happen, definitions function as what philosopher C.L. Stevenson has called 'persuasive definitions'. The latter typically restrict and specify the usually vague descriptive meaning of a word (e.g. 'democracy'), but leave its (positive or negative) emotive meaning unchanged and thereby (intentionally or not) influence the attitude of the addressee to the issue ('Democracy really is …') (Stevenson 1944, 210). Including specifying conditions in a definition (e.g. 'Palliative sedation is not life-shortening'), even if they have *descriptive* content, may prejudge the *ethical* evaluation ('Real palliative sedation is not life-shortening', i.e. 'hurrah for palliative sedation!' and, by implication, 'Boo to life-shortening!').

This is not to say that vague descriptive definitions are better than precise ones, or that definitions are better when they cannot possibly be suspected of prejudging the ethical issues. There is no real problem in *defining* continuous sedation at the end of life as 'not life-shortening'. Yet there *is* a problem if such a definition is used in a persuasive way, to settle disagreements in attitude toward end of life decision-making.

Moreover, in the context of clinical practice, the emotive loading of terms and definitions appears to carry a special weight. For example, Wilson and Seymour (2013 *forthcoming*) explain that confusion over what constitutes continuous sedation can lead to concerns and emotional burdens for nurses. Not knowing, in end of life situations, what one is involved in and contributing to, because of lack of clarity regarding what is being done, can indeed be very distressing. Some people object to the label 'terminal sedation' because the expression suggests intentional life-shortening. Others object to expressions like 'palliative sedation' because they are perceived as euphemisms. Thus, another important aspect of the 'definition issue' appears to be its role in coping by the health care personnel.

3.4 Artficial nutrition and hydration

Continuous sedation at the end of life can occur either *with* or *without* ANH. The main issue regarding withholding or withdrawing ANH, from both an ethical and a legal perspective,[3] seems to be that it makes life-shortening either probable or likely. Thus, in sedation without ANH, what causes the death of the patient may be the withholding or withdrawing of ANH, rather than the underlying disease or the sedation. The frequently cited Dutch national guideline on sedation maintains that, if sedation is *only* used for patients with a life-expectancy of two weeks or less (as this guideline recommends), the patient will die of her disease before dehydration or starvation can have any effect. However, some commentators (e.g. van Delden 2013 *forthcoming*, and Holm 2013 *forthcoming*) point out that accurately determining life-expectancy is nearly impossible, and that life-shortening thus frequently cannot be ruled out.

Although the relevance of withholding ANH is recognised by many commentators, there is some debate on whether initiating continuous sedation without ANH should be considered as a single decision, or as the combination of two decisions. The initiation of sedation might be justified, for example, by demonstrating the presence of severe refractory symptoms. However, justifying the withholding or withdrawing of ANH with

[3] As to the ethical debate regarding ANH, this is related to the debate regarding the distinction between ordinary and extraordinary means of preserving life. The latter has its roots in Thomas Aquinas' comments on suicide and bodily mutilation: 'A man has the obligation to sustain his body, otherwise he would be a killer of himself ... by precept, therefore, he is bound to nourish his body and likewise, we are bound to all the other items without which the body cannot live' (quoted in Cronin 1958, 48). In the 17th century, Juan Cardinal de Lugo, a Catholic moral theologian, refined the Catholic viewpoint by clarifying the distinction between ordinary and extraordinary means of preserving life (i.e. actions that are obligatory versus actions one is not required to perform in order to preserve life). As explained by de Lugo: '[A] man must guard his life by ordinary means against dangers and death coming from natural causes ... because the one who neglects the ordinary means seems to neglect his life and therefore to act negligently in the administration of it, and he who does not employ the ordinary means which nature has provided for the ordinary conservation of life is considered morally to will his death' (quoted in Henke 2007, 57). According to Henke, another important contribution de Lugo made to the Catholic moral tradition was the introduction of the concept of 'proportional benefit', implying that: '[W]ithin the domain of an ordinary means of preserving life, circumstances could exist which effectively rendered such a means extraordinary. Using the example of a man surrounded by fire and facing certain death by that fire, de Lugo illustrated the concept of proportional benefit. The man in the fire has at hand, in de Lugo's scenario, enough water to extinguish part of the fire, but not all of it, and if he used the water to quench some of the fire, his certain death would be delayed only a short time. In this case, the crucial element that determines proportional benefit is whether there exists a reasonable hope of recovery or continued life for an extended period of time, not simply a few extra moments' (Henke 2007, 58, footnote omitted).

an argument that, since the patient is unconscious (as a result of sedation), ANH is 'futile', has been labelled as a fallacious 'salami-slicing technique' (van Delden 2007 and van Delden 2013 *forthcoming*). Withdrawing or withholding ANH might be justified by demonstrating that the patient has requested just that, or by making a convincing case for the futility of ANH. However, some commentators (e.g. Holm 2013 *forthcoming*) point out that the concept of 'futility' is often misused in this context.

Sykes (2013 *forthcoming*), however, argues that, when properly performed, no life-shortening is involved in withholding ANH. His main argument is that the patients receiving continuous sedation have already stopped eating and drinking as a result of the dying process, so that withholding ANH does not add a life-shortening effect. He notes that administering ANH, on the contrary, may cause discomforting symptoms in the patient. At the same time, he warns that, if professional guidelines on sedation are to avoid giving the impression of sedation being 'euthanasia by stealth', they should not include a blanket prohibition on the use of ANH.

Gillian Craig, a geriatrician, in an article published almost two decades ago, wondered whether palliative medicine 'has gone too far' as regards its attitude towards ANH. In this article, which sparked a fierce debate in the literature, Craig expressed the following view:

> If death is imminent few people would feel it essential to put up a drip but ethical problems arise if sedation is continued for more than one or two days, without hydration, as the patient will become dehydrated. ... The only way to ensure that life will not be shortened is to maintain hydration during sedation in all cases where inability to eat and drink is a direct consequence of sedation, unless the relatives request no further intervention, or the patient has made his/her wishes known to this effect. (Craig 1994, 140)

Craig appears to suggest that, in the context of palliative medicine, a generally negative attitude towards ANH seems to exist, which may result in the wishes and emotional and ethical sensitivities of patients and their relatives being insufficiently taking into account. Since this, arguably important, aspect of the debate is not addressed further in this volume, Craig's comments deserve mentioning here:

> The consensus in the hospice movement seems to be that rehydration and intravenous fluids are inappropriate in terminal care ... Some say that a patient should be comatose, so as not to experience thirst, before it is morally acceptable to withhold or withdraw intravenous fluids. ... Thirst may or may not bother the patient. Concern about thirst undoubtedly bothers relatives. They will long to give their loved one a drink. They may sit by the bed furtively drinking cups of tea,

> taking care to make no sound lest the clink of china is torture to the patient. Anyone who has starved for hours before an anaesthetic will sympathise with dying patients who seem to thirst and starve for days. Nurses are taught that moistening the patient's mouth with a damp sponge is all that is necessary to prevent thirst. Relatives may not be convinced. ... Staff who believe strongly that intravenous fluids are inappropriate should not impose their views on ... relatives who request that a dying patient be given intravenous fluids to prevent dehydration or thirst. To overrule such a request is, in my view, ethically wrong. The only proviso would be if the patient had, when *compos mentis*, specifically said that he/she did not want a drip under any circumstances. No relatives should be forced to watch a loved one die while medical staff insist on withholding hydration. ... Such an experience is deeply disturbing and could haunt a person forever. Is all this agony worth it for the sake of avoiding a drip? ... The converse also applies. There will be occasions when the medical staff who are professionally involved would like to use a drip, but a knowledgeable relative requests no intervention. In this situation, the medical team will need to make a carefully balanced judgement as to whether intervention is essential or not. ... A doctor cannot be obliged to act contrary to his or her own conscience but equally doctors should bear in mind that relatives also have consciences ... Care must be taken to ensure that the burden of bereavement is not loaded heavily by distress about patient management in the terminal phase. (Craig 1994, 142-143, references omitted)

Clearly, the controversy surrounding ANH in end of life care, and especially with regard to continuous sedation, continues...

3.5 The Doctrine of Double Effect

The Doctrine of Double Effect (DDE) is one of the most commonly cited justifications for continuous sedation at the end of life. For DDE (in its most common interpretation, viz. the natural law interpretation, as explained in chapter 6) to be an adequate justification for continuous sedation, some conditions need be met. First, there must be some good effect as well as some sort of harm associated with sedation, and, second, the harm must not be intended *and* must not be the means to obtain the good effect.

As regards the possible harm done by sedation, as noted earlier, the ‘classic candidate’ is life-shortening. Different views are expressed as to whether this indeed a problematic aspect of continuous sedation at the end of life and, if so, whether and how it can be

avoided by, for example, including specific recommendations in professional guidelines on sedation. However, some commentators note that, even when no life-shortening is at issue, the permanent reduction or removal of consciousness itself constitutes a harm (Holahan et al. 2013 *forthcoming*; van Delden 2013 *forthcoming*; and Delbeke 2013 *forthcoming*).

The requirement for the applicability of DDE to justify continuous sedation is that the harm (whether life-shortening or consciousness-reduction or both) must be brought about unintentionally. The 'intention issue' is obviously a complex one. However, in this regard, it would seem instructive to take into account empirical studies of the practice of continuous sedation. As is clear from the literature review provided by Bruinsma et al. (2013 *forthcoming*), it is not uncommon that physicians performing continuous sedation at the end of life report that, when initiating the sedation, they *did* have an intention to shorten life. Moreover, the overview of clinical, pharmacological and practical aspects of sedation (for example provided by Porta-Sales 2013 *forthcoming*), shows that some drugs have consciousness loss as a *primary function*, which raises the question how those can be said to be administered without an intent to reduce consciousness.

In view of these and other complications, some commentators argue that invoking DDE to justify continuous sedation at the end of life is, at best, problematic and, at worst, unconvincing. Delbeke (2013 *forthcoming*) rejects DDE as a *legal* justification for continuous *deep* sedation, while we reject it as an *ethical* justification for this type of sedation (see chapter 6). In contrast, Huxtable and Horn (2013 *forthcoming*) acknowledge that DDE involves problems but nevertheless propose to hold on to it as a sort of compromise position.

3.6 Other parties involved

Another issue that is mentioned often in international literature is that sedation is a process rather than a decision. Not only the physician and the patient play a role in this process, but the patient's relatives as well as other carers are usually involved. From a *legal* perspective (e.g. Delbeke 2013 *forthcoming*) as well as from an *ethical* perspective (e.g. Porta-Sales 2013 *forthcoming*; Holahan et al. 2013 *forthcoming*), relatives can be important in decision-making when the patient has become incompetent. They then have a formal and legally recognised role as the representative of the patient, and should be involved in deciding what the patient would have wanted had she been

competent or, if that is impossible to determine, which course of action would be in her best interests.

Indeed, several professional guidelines on continuous sedation at the end of life mention the important role of relatives or other representatives of the patient. However, research cited by Bruinsma et al. (2013 *forthcoming*) indicates that the degree to which relatives are involved in the decision-making process varies significantly. Relatives often also have a role to play once sedation has been initiated. They often care for the patient, and the emotional impact on relatives of seeing their loved one, for example, in a state of continuous deep sedation, should not be underestimated (see chapter 8).

The role of nurses is also crucial, as is clearly shown by the literature review conducted by Wilson and Seymour (2013 *forthcoming*). Nurses often struggle with their (perceived) lack of involvement in decision-making at the end of life and, in the case of continuous sedation at the end of life, this may cause particular emotional and moral distress.

3.7 Determining depth of sedation/unconsciousness

A large degree of consensus seems to exist that sedation should be used *proportionally to the severity of the symptoms* the patient is suffering from. Indeed, this is emphasised in *all* the published sedation guidelines that we are aware of (e.g. Cherny et al. 2009; KNMG 2009). This implies that physicians and/or nurses need to ensure that a patient is not sedated too lightly (the patient's experience of suffering must be taken away), or too heavily (as warranted by the degree of severity of the symptoms). It would therefore seem to be very important to assess, as accurately as possible, how deeply the patient is sedated, so that sedation can be increased if it turns out to be too light, and decreased if too heavy.

The view that consciousness is morally significant has been argued for by various commentators, on the basis of different moral frameworks (e.g. Kamm 1999; Singer 2003). Thus, if consciousness is permanently reduced or taken away, this may be problematic from an ethical perspective (e.g. Janssens et al. 2012). Hence proportionality is important, yet 'obtaining' the 'proper' level of consciousness is difficult in practice for a number of reasons. Accurately assessing depth of sedation is difficult enough for anaesthesiologists in cases where patients are temporarily sedated to undergo surgery (Shafer & Stanski 2008), yet even more so for patients who are in a

bad physical condition and in their last stages of life. While the problem of *potentially undetected awareness* has been widely researched for patients undergoing anaesthesia (e.g. Mashour 2010), hardly any research on this topic exists for patients who are continuously sedated until death, implying the possibility that at least some *seemingly* sedated patients are actually experiencing (some degree of) suffering.

Probably the most commonly used tool to assess depth of sedation in cases of continuous sedation is *basic clinical assessment*, where a physician observes whether the sedated patient is comfortably asleep. If the patient shows signs of being awake (for example groaning while being washed or handled), dosages can be adjusted. However, various studies have shown that this approach is problematic since it reduces 'consciousness' to 'responsiveness to certain stimuli', whereas recent research has shown that patients can be *unresponsive and yet aware* (Noreika et al. 2011). Moreover, the accuracy of clinical assessment is likely to depend on how often the physician doing the assessment has come into contact with continuously sedated patients at the end of life.

In some professional guidelines, the use of sedation scales has been proposed (e.g. Cherny & Radbruch 2009). Indeed, using such scales has several advantages (Rinaldi & De Gaudio 2006), as it allows for scores to be checked by colleagues or for measuring over time to monitor fluctuations in depth of sedation. However, only a few sedation scales have been validated for palliative care patients, and questions remain concerning both the effectiveness and the invasiveness of sedation scales. With regard to *effectiveness*, the concern is voiced that sedation scales, like basic clinical assessment, measure response to stimuli, which is not the same as consciousness and thus raises doubts on the effectiveness of such scales (Alkire et al. 2008). As regards *invasiveness*, admittedly, the use of scales does not require putting patients on machines, yet in an important sense their use *is* invasive, for the physician or nurse needs to stimulate the patient, for example by calling out her name, prodding, shaking or even providing painful stimuli.

Instead of using clinical assessment or scales, one could look directly at brain activity, by, for example, analysing a patient's EEG. However, a raw EEG produces a great amount of information that is not relevant for measuring consciousness, and interpreting this information requires a lot of expertise. Techniques have been developed that process the EEG signal to generate a more readily usable value. An example of such techniques is the so-called 'BIS monitor' (for 'bispectral analysis'), which analyses a single EEG to produce a number on a scale ranging from 0 (inert) to 100 (awake state), making it a highly practical and easily interpretable tool. This technique merely requires placing an electrode patch on a patient's forehead, and so does not require patient stimulation.

Another advantage is that the BIS monitor allows continuous measurement. Some research exists that indicates the applicability of this technique to patients who are continuously sedated at the end of life (Liu et al. 1996), however more research is urgently needed if the requirement of proportionality is to have real substance.

3.8 Refractory symptoms and existential suffering

Continuous sedation at the end of life is usually thought of as a last resort measure, to be applied when symptoms have become refractory. As explained earlier, a symptom is refractory when there is no other method than continuous sedation that can be used for palliation within an acceptable time frame and/or without unacceptable adverse effects (Cherny & Radbruch 2009).

Sometimes it is observed that the high frequency of continuous sedation in Belgium, The Netherlands, and the UK, indicates that this practice is *de facto* also being used in patients with *non*-refractory symptoms. There is a lot of debate as to whether the studies in these different countries really consider the *same* phenomenon, and thus whether the numbers can be compared. Yet, even if the responding physicians in different countries may have had different understandings of the questions they were asked, one might wonder whether frequencies of continuous sedation of up to 12.3 % (of all patients who died in The Netherlands in 2010, see Onwuteaka-Philipsen et al. 2012) or up to 14.5% (Belgium in 2007, see Chambaere et al. 2010) are compatible with a 'last resort'-option.

What defines refractoriness is not the nature of a symptom, but *how* one may fail to treat it. Failure can have many faces in this context: a treatment method may be available, but it may take too long to become effective in order for it to be of any use to a dying person; there may be no treatment at all; a treatment may be available, yet not adapted to the setting in which the patient finds herself (e.g. home versus hospital); a treatment may exist, yet not be known or sufficiently mastered by the patient's physician; the available treatment may be one that alleviates the initial problem (e.g. severe pain) in time, but at the cost of other equally or even more distressing symptoms (e.g. hallucinations). Thus, in fact 'refractoriness' is an outcome of the patient's disease symptoms and the available medical resources, including the physician's abilities. This has a bearing on the frequency question: the fewer palliative care resources available (*ceteris paribus*), the higher the number of refractory symptoms. Thus, setting a base-line of what might be a 'normal' frequency of refractoriness is a very tricky matter.

Last resort considerations are particularly complicated in cases of so-called 'existential' or 'spiritual' suffering in the patient. We argued earlier (in section 1 of this Introduction) that the term 'symptom' is vague and may cover a range of problems that does not properly fall under the 'action radius' of medicine (the 'Ivan Ilych cases'). Yet, allowing a patient to die a good death may require bringing existential suffering within the reach of medical action. The extension of permissible indications for continuous sedation to existential suffering however is highly controversial. Existing professional guidelines contradict each other in this respect, in that some include existential suffering as an indication for continuous sedation at the end of life, while others do not.

3.9 Patient requests for CDS; the non-imminently dying

Another issue that is addressed by several contributors to this volume (e.g. Delbeke 2013 *forthcoming*; Holm 2013 *forthcoming*; Orentlicher 2013 *forthcoming*) is the meaning of a patient request or of patient consent for a decision to initiate continuous sedation at the end of life. Professional guidelines emphasise that continuous sedation should be preceded by patient consent (or a surrogate for it). Epidemiological findings show however that patient consent is not always sought and obtained by the physician (Bruinsma et al. 2013 *forthcoming*). How much of a problem is this?

Last resort considerations as well as double effect considerations can survive perfectly in the absence of consent. Autonomy-based considerations (which emphasise the need for consent) are independent from, and supplementary to, the lines of reasoning implied in last resort and double effect considerations. Moreover, some commentators (e.g. Battin 2013 *forthcoming*) argue that, even when consent to continuous sedation at the end of life is obtained, the patient may not have been well informed, or may even have been misled with respect to what she is consenting to.

It has also been observed (e.g. Orentlicher 2013 *forthcoming*) that the restriction of continuous sedation to patients expected to die within no more than two weeks, leaves a segment of the patient population without 'arms' in the face of refractory symptoms. Indeed, if this restriction, which is typically mentioned in professional guidelines on sedation, is observed in practice, non-imminently dying patients have no access to the benefits of continuous sedation, even if they ask for it, and even if potential alternatives like euthanasia or physician-assisted suicide are legally unavailable.

Holm (2013 *forthcoming*) and Battin (2013 *forthcoming*) also draw attention to the implications of the increased frequency of continuous sedation for our *ars moriendi*. Although there are obvious benefits to this end of life practice, alleviating and controlling pain is at risk of becoming the *sole overriding value* served by medicine at the end of life. This value, albeit a very important one, risks systematically overriding the value of life and the value of patient autonomy. This may result in a 'new wave' of paternalism.

Understandably, the devotion to eliminating suffering is perfectly in line with the physician's ethos: it allows her to focus on the technical problems of titrating drugs, monitoring side-effects and administering drugs to diminish their impact. In other words, the ground that is familiar to physicians in any specialty. In The Netherlands, there has been a shift from euthanasia to continuous sedation, and this has been attributed to the psychological and administrative burdens - for the physician - of performing euthanasia (van der Heide et al. 2007). Although it may be understandable from both a practical and ethical perspective, this shift indirectly also implies a choice for technicality over going through difficult discussions with patients and their relatives. The speed at which continuous sedation is spreading in end of life care is perhaps an indication that the habits of high tech medicine are gaining ground in end of life care.

3.10 Safeguards and 'Normal Medical Practice'

In the opinion of many commentators, continuous sedation at the end of life is an example of 'normal medical practice'. We do not have the space here for an in-depth analysis of the question what 'normal medical practice' might be. The main idea, however, appears to be that if the medical profession has internally regulated, either by practical consensus or by guidelines, what practice to use in order to address certain problems, then the practice is 'normal'. For example, when Australian physicians regularly refer their patients to chiropractors and osteopaths for complementary treatments, this constitutes 'normal medical practice', because it is sufficiently widespread and accepted (Easthope et al. 2000). When physicians shorten their patients' lives by withholding treatment, according to the internal norms of the medical profession regarding good practice in this context, this constitutes 'normal practice'.

What makes a medical practice 'normal' is thus that internal regulations (e.g. deontological codes of professional guidelines) are deemed sufficient for containing

possible abuses. Yet when physicians seek to obtain the same result, at the patient's request, by using lethal means, the practice is *not* normal (Ten Have & Welie 1992). We would submit that, what makes such practices 'non-normal' is the idea that, in order to contain the dangers inherent in deliberate killing, a stronger form of regulation is needed, one that is laid down in special laws. In countries where euthanasia and physician-assisted suicide are legalised, the non-normal character of deliberate life-shortening is signalled by the obligation on physicians to report these practices to a (quasi-)government body that controls whether the safeguards for good medical practice have been observed. The scrutiny of these practices is thus more thorough, and more external, than for 'normal' medical practices.

How is this relevant to continuous sedation at the end of life? It is frequently argued that this constitutes normal medical practice, because its aim is not to shorten life and because the regulations governing it have been laid down in professional guidelines (i.e. 'lesser' regulation). However, some commentators (e.g. Janssens et al. 2012; Orentlicher 2013 *forthcoming*; Delbeke 2013 *forthcoming*; Holm 2013 *forthcoming*) state, or at least imply, that continuous sedation at the end of life is not so normal. First, as mentioned earlier, its non-life-shortening nature is contested. Second, some argue that a patient who has permanently lost consciousness, while remaining alive, has lost just as much as a patient who has lost both consciousness and life: the possibility of having meaningful experiences. Society has a stake, according to these commentators (e.g. Battin 2013 *forthcoming*), in controlling the tendency of indications of refractoriness to expand into existential and psychological suffering, and to question the 'standard way of dying' that is being imposed on terminal patients.

An important practical question that arises from all the above considerations is whether (certain types of) continuous sedation at the end of life should be reported to an official body, as is the case for physician-assisted suicide and euthanasia in the jurisdictions where these practices have been legalised.

3.11 References

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Part 2

Ethical issues

Chapter 4
Continuous deep sedation at the end of life and the 'natural death' hypothesis

Update of a published journal article:

Raus, K., Sterckx, S. and Mortier, F. (2012) "Continuous sedation at the end of life and the 'natural death' hypothesis". *Bioethics* 26(6):329-36.

4.1 Introduction

Since the 1990s a new end-of-life decision (ELD) has increasingly been debated and discussed, namely continuous sedation at the end of life. As was argued in the introduction, many different types of sedation can be distinguished in medical care. Sedation can for example be light (the patient can still be woken with mild arousal). It can also be deep, but only used for a short time (for example anaesthesia for surgery).This chapter will focus on one particular form of sedation, namely sedation that is both deep and deliberately continued until the patient dies: continuous deep sedation (CDS). The reason for this focus on CDS is the fact that this is the most controversial type of sedation and that this chapter will rely on empirical data that concerns only the deep form of sedation, and so the argument developed need not necessarily relate to certain other types of sedation. Relating back to the definition discussed in the previous chapter, CDS could thus be defined as the practice whereby one administers sedative drugs resulting in the continuous and total loss of a patient's consciousness until death follows. According to the standard view, CDS should always be a 'last resort' option (e.g. Quill et al. 2000; Cherny et al. 2009), and thus 'should only be implemented in the rarest of circumstances' (Levine 2008, lines 18-19).

Nonetheless, recent data from the UK (Seale 2009), The Netherlands (Rietjens et al. 2008; Onwuteaka-Philipsen et al. 2012), and Belgium (Bilsen et al. 2009) clearly show that the incidence of CDS in all three countries is remarkably high. The incidence in the UK is highest, with CDS occurring in 16.5% of all deaths. In The Netherlands and Belgium multiple studies have been conducted, which allow data from different periods to be compared. Furthermore, these studies have often used the same methodology, making the comparison very much more reliable. In both The Netherlands and Belgium, a sharp increase in the use of sedation has occurred. In Belgium, the practice was used in 8.2% of all deaths in 2001, but in 2007 its incidence had increased to 14.5% of all deaths (Bilsen et al. 2009). In The Netherlands, the use of CDS in conjunction with the withdrawal of all life-sustaining treatments increased from 5.6% of all deaths in 2001, to 7.1% of all deaths in 2005 (Rietjens et al. 2008). According to available research, the total incidence of CDS in the Netherlands in 2005 was 8.2% (van der Heide et al. 2007), but this number increased to 12% in 2010 (Onwuteaka-Philipsen et al. 2012). These countries are comparable as far as the degree of availability of medical technologies and access to palliative care are concerned, thus we have good reasons to believe that these data can be compared. Furthermore, data on CDS are available for some other European

countries, for example for Italy and Switzerland (Miccinesi et al. 2006), where the incidence was 8.5% (for Italy) and 4.8% (for Switzerland) of all deaths in 2001.

These incidences are surprisingly high, especially in view of the fact, noted above, that CDS is usually claimed to be only advisable as a 'last resort', and so presumably only in rare cases. Indeed, continuous sedation to a lighter degree was not even included in the research quoted from above, so including this type of sedation would only increase the number of patients receiving sedation at the end of life. Different hypotheses can be formulated to explain the fast growing incidence of CDS. In this paper we shall focus on one such hypothesis, which we call the 'natural death' hypothesis.

4.2 The 'natural death' hypothesis

The 'natural death' hypothesis can be formulated as follows: acceptance of CDS has spread rapidly because death after CDS can be perceived as a 'natural' death by medical practitioners, patients' relatives and patients.

In the debates on CDS it is very often emphasized that the practice has no life-shortening effect, and this has led many commentators to consider CDS a 'natural' process'. The American Medical Association, for example, argues with regard to CDS that it 'may also allow the natural process of terminal disease to take place' (Levine 2008, 4). The moral philosopher Torbjörn Tännsjö has said in relation to CDS that: 'Death is certainly sought, but not actively, only as the end of a natural chain of events. Death is allowed to take place in the way it does' (Tännsjö 2004, 20-21).

This view seems to be shared by most clinicians, as can for example be found in Hasselaar et al. (2009), who investigated whether the practice of CDS had changed after the Royal Dutch Medical Association created a guideline specifically for CDS.[1] Hasselaar et al. (2009) concluded that 'physicians [after the creation of a guideline] more often regarded continuous sedation as a natural way of dying' (Hasselaar et al. 2009, 431). A total of 60.7% of physicians agreed that death after CDS is a 'natural' death.

[1] The method they used was a comparison of a baseline study (2003-2005) with a follow up study (2007). One of the things physicians were asked was what they perceived as the differences between euthanasia and CDS. In the baseline study 53.2% of doctors agreed with the statement: 'During sedation, the patient dies a natural death'. During the follow up study this number had increased to 60.7%.

However, these views are questioned. Margaret Battin, for example, questions whether we can properly consider death after CDS as a 'natural' death. She claims that death after CDS is the opposite of natural, for CDS *causes* death. She says:

> The death itself is not "natural," [...]. The airy, rather romantic notion of "natural" death usually refers to death that results from an underlying disease, but in terminal sedation death typically results from or is accelerated by dehydration. (Battin 2008, 28)[2]

We want to analyse more closely the apparent relationship between naturalness of death and CDS. Indeed, CDS requires the active administration of sedative medication and thus the question arises as to how a dying process which is characterised by active medical interventions could be perceived as 'natural'. Hence we shall investigate what a 'natural' death might be and whether the portrayal of death after CDS as 'natural' is valid.

4.3 CDS as a 'natural' death?

The first question that arises is what it means to call a death 'natural'. A provocative view on the subject of 'natural' death has been put forward by Ivan Illich in his book *Medical Nemesis.* He discusses the far-reaching medicalisation of society and its effect on how people die. He notices that, historically, 'the medicalisation of society has brought the epoch of natural death to an end' (Illich 1979, 210). For Illich there was no room for a concept such as 'natural' death in an era where death is characterised and controlled by the medical world.

Illich's concept of 'natural' death is the concept of a death where nature determines the timing of death. This stands in contrast with the 'medical' or 'technical' death where

[2] Two important things have to be noted here. The first is that Battin uses the term 'terminal sedation', and not CDS, but this refers to the same practice as the one we call 'continuous deep sedation at the end-of-life'. Secondly, when Battin questions the 'naturalness' of death after CDS, she is primarily targeting that form of CDS where all artificial hydration and nutrition is withheld. For Battin these are the cases were CDS most clearly causes death. See also Quill et al. (2004). Like Battin, these authors note that patients receiving CDS often die of dehydration rather than the underlying disease. We will return to the subject of the withholding of artificial hydration and nutrition.

doctors control almost every aspect of the dying process. In this regard it is notable that palliative care is itself an example of the thorough medicalisation of dying.

After Illich, the concept of 'natural' death did not disappear, but its emotional meaning did change under the influence of the medicalisation he mentioned. Authors such as Seymour (1999) and Howarth (2007) note that, in the more recent literature, 'natural' death stands in opposition to an 'unnatural' or 'medical' death. The same literature often criticises the 'medical' death and idealises the 'natural' death. Applying the label 'natural' becomes a way of framing a death as 'good', and using the term 'medical' or 'medicalised' becomes a way of indicating a bad death. Indeed, 'natural' death seem to have moved from being a descriptive concept to being something of a normative ideal. One of the ways in which the concept of a 'natural death' receives a more positive value, is by means of a technique related to the technique known in linguistics as 'semantic prosody'. Here more or less neutral words receive a more positive value by frequently co-occurring with more clearly positive words. A nice example is a statement by de Graeff & Dean (2007) in an influential paper on CDS, or Palliative Sedation Therapy, as they call it:

> The desired outcome of PST is symptom relief and a peaceful, quiet death by the natural course of the disease. (de Graeff & Dean 2007, 78)

These authors seem to use 'natural' as a positive value by associating it with a peaceful and quiet death. This way of association is common in literature on continuous sedation

Thus, by calling death following CDS 'natural' or at least resembling a 'natural' death, one seems to be: (1) portraying it as morally good and (2) contrasting it to other – 'medical' – deaths. We will come back to this. Once we have a clearer picture of what is usually meant by 'natural' (e.g. the opposite of 'medical'- a death without medical interference), we can see how it might apply to CDS.

In view of the fact that a medical practitioner administers sedatives to take away a patient's consciousness and then monitors the patient until death occurs, CDS is an essentially medically controlled practice. In our view, the label 'natural' therefore cannot be unproblematically applied to the *nature* of the practice, but it might apply to the *appearance* of the practice to medical practitioners, patients' relatives and patients

themselves (e.g. Rietjens et al. 2004[3]). Seymour et al. (2007) have noticed that sedation *mimics* a natural death:

> Arguably, palliative sedation mimics a death occurring in deep sleep: one version of the good or 'natural' death which is popular in the developed world. (Seymour et al. 2007, 1687)[4]

If this were true, it would mean that the traditional idea of a 'natural' death and death after CDS share certain characteristics, or at least certain *perceived* shared characteristics. A review of the available literature has revealed the following characteristics as key elements of a 'natural' death: (1) deep sleep, (2) fading away, (3) internal causes, (4) no prolonging or shortening of life, and (5) no agency. We would like to briefly go into each of these potential similarities between 'natural' death and death following CDS.

Deep sleep

One version of the natural death – and probably the most popular version – is death occurring in a deep sleep; one slips away quietly.

This can also be observed in CDS. Indeed, it is arguably the very purpose of the practice. When the patient's consciousness is lowered or removed, she is seen to be in a state which resembles deep sleep. Chater et al. (1998), for example, claim that CDS is all about 'deliberately inducing and maintaining *deep sleep*' (Chater et al. 1998, 257).

Fading away

Another thing that is sometimes associated with a natural death is the gradualness of the process. The classic example is that of somebody dying at home, surrounded by her family. She spends her last days saying goodbye to everybody before slowly slipping away and eventually dying. In this respect, reference can be made to Pool (2004) who

[3] They interviewed 410 physicians on their most recent use of CDS. In 37% of the cases both euthanasia and CDS were suggested during the process of decision-making. In these cases one of the main reasons for preferring CDS over euthanasia was that the patient herself viewed CDS as less disturbing to the natural process of dying.

[4] Seymour et al. as well as some other commentators use the term 'palliative sedation' to refer to what we call CDS.

notes: 'I think there is a general consensus that, at the very least, natural death can be said to consist of fading away peacefully at the end of a long and full life' (Pool 2004, 963).

This process of 'fading away peacefully' is present in CDS, even more so when one realises that in the UK, for example, sedation at home is quite common (Seale 2009). See also the quote above by de Graeff & Dean (2007) which talks about a 'peaceful, quiet death' (de Graeff & Dean 2007, 78).

Internal causes

Some authors (Oehmichen & Meisser 2000; Sandman 2005)[5] claim that the classical difference between a 'natural' and a 'non-natural' death is that a natural death is caused only by internal causes, while a non-natural death is not. In cases of euthanasia, homicide or suicide, the cause of death is something external. Medical interventions are to be considered as 'external' physical influences, from this point of view, and as such are constituents of an 'unnatural' death.

This characteristic of 'natural' death is also mentioned, for example, by Howarth (2007) who says with regard to a 'natural death' that: 'the cause of death is located within the body and was not a result of human agency' (Howarth 2007, 165). We will come back to the question of agency below.

Proponents of CDS frequently emphasize that a death following CDS shares the 'internality' of its causes with a 'natural' death. They admit that medical interventions (sedating the patient and sometimes withholding food and fluids) are present, but these are said to be not the 'real cause' of death. The key idea in this type of reasoning is that the patient dies of 'the underlying disease', which is an obvious internal cause. This idea can be found in many of the existing guidelines on CDS.

No prolonging or shortening of life

Another supposed aspect of a 'natural' death is the fact that the *timing* of the dying process is determined solely by the disease, in contrast to a medical death, where

[5] Both articles talk about the classical conceptions of 'natural' death, but reject the pertinence of the concept in general.

physicians take control of the dying process (Pool 2004, 963).[6] One way to increase the likelihood that the cause of death is solely the underlying disease is to make sure the life of the patient is neither shortened nor prolonged by a medical intervention. High (1978) has argued that:

> "Natural death" means that which is inherent and spontaneous; not artificial or contrived or prolonged. (High 1978, 41)

According to this view, for example, a person with a terminal illness who dies after having been kept alive for a long time by a machine is not considered to have died a natural death, in view of the life-prolongation.

In debates surrounding CDS, the aspect of the possible prolonging or shortening of life is a contentious issue. It is often claimed that CDS results in no or very little shortening of life. Chiu et al. (2001) have compared groups of terminal cancer patients who received CDS and groups that did not and found that the median survival did not differ between these two groups. They concluded that CDS has no life-shortening effect. This type of research has been repeated, with very similar results (Morita et al. 2001; Sykes & Thorns 2003).

No agency

This characteristic of 'natural' death is similar to some of the previously mentioned characteristics, but in our view it is sufficiently important to discuss separately. As noted earlier, one of the supposed characteristics of a 'natural' death is the fact that its timing is determined solely by an underlying disease. This also means that in the case of a 'natural' death, there is no agency by doctors, nurses or relatives, in the sense that what happens during the dying process is not the result of a deliberate human decision. The question here then is *not* – like with the characteristic of 'internal causes' – what actually caused the death, but where the responsibility for the death lies. In the case of a 'natural' death, nobody can be held responsible for the death. A similar claim is made with regard to CDS.

[6] He thinks that an 'unnatural' death is synonymous with a death controlled by medicine. See also Hart et al. (1998), and Seymour (1999). These articles draw on extensive sociological literature, and seem to underpin the view that the ideal of a 'natural' death is a cry for not letting doctors determine the timing of the dying process.

4.4 Critical evaluation of the standard view

The previous section described the standard view of death after CDS. However, we believe that this view is fundamentally wrong. As we will argue in this section, CDS involves a complex *mise-en-scène* with the goal of enabling the various parties concerned to cope more easily. We agree with authors such as Seymour et al. (2007) and Billings & Block (1996) that the resemblances between a death following CDS and a 'natural' death are merely a *mimicry* or a *simulation*. To prove this point we will critically discuss the various characteristics mentioned above that 'natural' death and CDS supposedly share.

Earlier we noted that death following CDS and 'natural' death seem to be similar in the sense that both involve dying in a 'deep sleep'. However, this similarity is only one of appearance. What is called 'deep sleep' in CDS is a medically induced sleep: an induced coma. There can be no question about it that this 'medical' sleep differs from what might be called a 'natural' sleep precisely because it is caused intentionally by medical means.

The second possible similarity was that death after CDS and 'natural' death both represent a gradual process. Nevertheless, in CDS the dying process is *made* to proceed gradually. CDS usually consists of slowly increasing a patient's medication dosage, while gradually withdrawing treatment. The similarity therefore only exists at the level of appearance.

The third candidate for similarity – that both a 'natural' death and a death following CDS are solely due to internal causes – is heavily debated. We believe that determining the exact cause of a patient's death is very difficult in most circumstances – especially in cases of non-sudden deaths, such as deaths after CDS. To simply claim that the underlying disease is the sole cause of death seems to be based on an overly narrow perspective on the situation; several causes can be presumed to be at work. When CDS is combined with withholding or withdrawing of all food and fluids, it is clear that that this will play a causal role (small or large) in the dying process of the patient.

No prolonging or shortening of life – the fourth similarity mentioned above – is linked to the 'internal causes' issue, and is equally debatable. Proponents of the standard view of sedation use research such as Chiu et al. (2001) – discussed earlier – to argue that life is neither shortened nor prolonged by CDS. However, in this context we believe the (lack of) artificial administration of food and fluids to be particularly relevant. Setting measurement problems aside, CDS where artificial hydration and nutrition are administered might be said not to result in shortening of life, but when dealing with

cases where food and fluids are withheld, a different situation arises. CDS without hydration and nutrition makes up a large part of all CDS. In The Netherlands, for example, Hasselaar et al. (2009) found that artificial hydration and nutrition was absent in 78.8% of all CDS cases in 2007 (Hasselaar et al. 2009, 434). In Belgium, CDS *with* artificial hydration and nutrition was used in 59% of all CDS cases in 2005-2006, while CDS *without* artificial hydration and nutrition was used in 41% (Van den Block et al. 2009, 83). This makes the problems related to artificial hydration and nutrition hard to ignore.

In reaction to such observations, two replies are sometimes given. According to the first, the patient dies in a time span that is too short for the withholding of food and fluids to have had any effect.[7] The second reply is that stopping eating and drinking can be a natural part of a dying process (Callahan 2004).

With regard to these replies, we would say that, in many cases the decision to forego all administration of food and fluids is taken by a doctor. As such, it is a medical intervention and therefore just as unnatural as the provision of artificial hydration and nutrition. Moreover, even if it would be the case that stopping all eating and drinking is a natural part of dying (or more natural than the provision of ANH), the conclusion that life is not shortened by this decision is not warranted. As was already argued in the introduction of this thesis, although some research seemingly shows that CDS does not shorten life, there are reasons to doubt this claim.

We are of course aware of the fact that not all deaths following CDS are alike in the respects that seem to distinguish them from 'natural' deaths. CDS may be initiated a couple of hours or days before death, or it may be continued over longer periods. In cases where the duration of sedation is very short, life shortening is much less likely to occur than in cases where the duration of sedation is longer. Cases where the patient dies shortly after institution of sedation can therefore be said to involve a *more natural* death than cases characterised by longer periods of sedation. Some cases of CDS therefore come closer than others to being a 'natural death' (in the sense, as mentioned earlier, of involving no additional life shortening – due to human intervention – as compared with the life-shortening due to the disease).

[7] This argument is used, for example, in the guideline on sedation, issued by the Royal Dutch Medical Association in 2009 (KNMG 2009, 29). Some data can be used to support this line of reasoning. See Rietjens et al. (2008). According to this source 94% of all patients receiving CDS in the Netherlands die within the time span of one week.

The last potential similarity between death after CDS and 'natural' death was an absence of human agency. Admittedly, CDS is a gradual process, which makes the medical practitioners' agency less clear (e.g. Billings & Block 1996). Moreover, different people are involved in the process of taking care of a sedated patient, allowing a diffusion of responsibility. Furthermore, CDS does not necessarily require revisions of treatment once the patient has been sedated, and therefore does not necessarily require more decision-making.[8] However, claiming that there is *no* agency in CDS seems to involve a denial of the complexity of human agency. A great deal of agency is involved in sedating a person and then continuously monitoring her until she is dead. This issue of monitoring continuously sedated patients is very interesting in this respect and will be discussed more in depth in chapter 5.

Besides, human agency starts long before the sedation. Earlier on in the disease process a decision may have been taken, for example, not to administer a certain treatment, and that decision may have influenced the condition of the patient and possibly also created a need for CDS.

Our more general criticism of the standard view of death after CDS as a 'natural' death is that it is based on 'time-slicing'. The standard view focuses on the last days of a patient as the only relevant days. From that point of view, in many cases it may indeed appear that there is only an internal cause, no shortening or prolonging of life and no (real) human agency. When we look at the bigger picture, however, we see a different image. CDS frequently occurs at the end of a curative or palliative process, and this needs to be taken into account in both the factual and the normative evaluation of this practice.

4.5 The portrayal of death following CDS as 'natural' increases the acceptance of CDS

It was argued that CDS is portrayed as providing a 'natural death', but the question rises who is doing the portraying and why? According to Battin (2008), certain aspects of CDS are being 'sanitized' and 'obscured' to make the practice more acceptable. Indeed, a complex set of mechanisms seems to be at work that facilitates the use of CDS as a

[8] Even though, of course, the decision not to increase sedation in a certain case could also be considered a decision.

preferred end-of-life practice. Each of these mechanisms has been described in other (i.e. non-CDS) contexts, for example by Bandura (2002) and Seymour (2000).

Bioethicist John Harris, in his book *The Value of Life*, also argues that regarding a death as 'natural' allows a doctor to distance herself from that death and helps her fit her own role more easily into the accepted role of a medical worker (Harris 1994).

Euphemistic labelling

The use of euphemisms to describe a practice is a widely used technique to make the practice in question more acceptable. Bandura (2002) discusses this technique as an element of what he calls 'moral disengagement'. We can find an example of the use of euphemisms in another end-of-life context: 'Do-not-resuscitate' (DNR) codes. Some authors find the label 'DNR' too negative and fear that many relatives are scared into asking that the patient be resuscitated (McCoubrie 2008; Venneman et al. 2008). They argue that 'DNR' should be replaced by 'allow natural death' (AND). The practice would remain exactly the same, but the 'AND' label would make more relatives accept the code. Venneman et al. (2008) have tested this hypothesis, and found that relatives were indeed more likely to accept an 'AND' code than a 'DNR' code, and concluded that the name should therefore be changed.

With regard to CDS, we can clearly see this mechanism at work. The fact that CDS is often referred to as 'palliative sedation' can be regarded as an example: the term 'palliative' gives CDS a positive connotation. To say that a sedated patient is put into a 'deep sleep' rather than a 'medically induced coma' is another example.

Advantageous comparison

A different mechanism involves comparing a practice with something that is regarded as morally good or morally neutral. This technique is also discussed by Bandura (2002), who calls it 'advantageous comparison' (Bandura 2002, 105). When applied to CDS, it means that by equating death after CDS with 'natural' death, key characteristics and connotations of 'natural' death are transferred to death after CDS. 'Natural' death, for example, has an important connotation of inevitability, implying that nobody is responsible for the death. The comparison allows CDS to receive the same connotation of inevitability, which would imply a weakening of personal responsibility for everyone involved. However, this is problematic, since, as noted earlier, CDS involves various important decision stages.

Diffusion of responsibility

One of the most important mechanisms to facilitate 'moral disengagement' is the diffusion of responsibility. As a general technique it is discussed by Bandura (2002). Seymour (2000) has analyzed it as a strategy used by medical practitioners in intensive care units. Diffusion of responsibility obscures the individual responsibility of everyone involved.

The relevance of this mechanism for our topic is that, in medical settings (particularly institutional ones), there is rarely just one person making a decision. Decisions are frequently made in the context of a medical team, or there may be shared decision-making with the family of the patient or the patient herself. As a result the feeling of personal responsibility diminishes and CDS becomes more acceptable. This is, of course, not always the case and some research into nurses' involvement shows that nurses are not always involved in the decision-making process (Inghelbrecht et al. 2011). However, even in these cases nurses are involved in the care for the patient, and so responsibility can still be shared in these cases.

Seymour (2000) shows that the technique of 'diffusing responsibility' works and is being used in medical settings. The denial of agency discussed earlier may well provide a coping strategy for everyone involved. With agency comes responsibility and without (clear) agency one cannot so easily be said to be responsible for a patient's death.

Labelling as a 'last resort'

We have noted above that CDS is usually claimed to be a last resort. Such a claim may well facilitate the use of this practice. By calling CDS a last resort, one is basically saying that when CDS is used, there is no alternative. This minimises the weight of the decision-making role of the physician; her hands are tied. It also contributes to the general idea of death after CDS as something inevitable and as such it reduces agency and hence also personal responsibility. Chapter 6 of this dissertation reports data from a focus group study which confirmed that for many physicians and nurses it is indeed important to use continuous sedation only as a last resort.

Through the various coping mechanisms mentioned above, CDS is made to appear as a morally acceptable practice, and the labelling of death following CDS as 'natural' plays a very important role in this construction. Indeed, medical practitioners sometimes seem to use the concept of 'natural death' with the aim of increasing the likelihood of acceptance of particular end-of-life practices. In her book *Critical moments – death and*

dying in intensive care, Seymour (2001), when discussing the experience of 'natural death', differentiates between the 'front stage' and the 'behind the scenes' (Seymour 2001, 90). The 'front stage' refers to the intensive care as perceived by patients' relatives. However, the experience of the clinicians, who are 'behind the scenes', is completely different:

> [C]linicians struggle to establish whether or not death is imminent and try to construct a case that justifies the withdrawal of 'active' medical treatment such that 'natural death' can occur (Seymour 2001, 90).

This shows that relatives and physicians can have a completely different perspective on a certain medical practice. A practice can easily have two faces, and appear to be one thing to a relative and a completely different thing to a physician. We believe that the depiction of death after CDS as 'natural' is part of this 'front stage' façade. Moreover, the perspective of patients' relatives (and patients themselves) sometimes seems to be deliberately shaped by physicians, including through the language they use.

In addition to the 'advantages' offered by the construction of the dying process as 'natural', CDS allows the physician control over the dying process. Portraying dying as 'natural' facilitates coping, but the practice of CDS itself has some secondary advantages: as a last resort option it justifies unilateral physician decisions; it provides a solution to a lack of (communication about) advance care planning; in countries where euthanasia is legalised it avoids administrative burdens and exposure to government/legal review; and the decision to initiate CDS can be seen as a simple 'technical' continuation of preceding (palliative) medical interventions.

4.6 Concluding remarks

In the previous sections we have tried to show that death after CDS is frequently seen and labelled as 'natural' death. We have also argued that this is related to a larger set of mechanisms which facilitate the use of CDS.

However, one might concede that dying under CDS is not 'natural' in the strict sense of involving no human agency, etc., and nevertheless ask: 'So what? Is CDS not the way of dying that comes closest to natural death and therefore is it not preferable to alternative medical end of life practices, and certainly to providing a patient with lethal drugs in order to end her life or to administering such drugs?'. Let us call the view that

corresponds to this objection the 'minimum impact conception of ethics at the end-of-life'. This may be compared to the widely accepted view in wildlife ethics that concedes that wilderness conditions cannot really be achieved in ecosystems that suffer human impact, but that human intervention should be used to restore wilderness conditions as authentically as possible. Human intervention, according to this view, is precisely what is needed to restore as far as possible the 'naturalness' of ecosystems. Why not extend the analogy to end-of-life ethics and argue that, although it is true that CDS does not constitute a natural death but merely mimics it, it has the merit of coming closest to a natural death? One might even add that death under CDS is better than natural death because in addition to mimicking natural death, CDS allows physicians to combat or eliminate clearly undesirable aspects of some natural deaths, such as excessive pain or other highly burdensome symptoms.

We would reply that the 'minimum impact conception' of proper ethical conduct at the end of life begs the question. It is true that *if* natural death is the best way of dying, then a way of dying which approaches naturalness more will be preferable to one which approaches it less. It certainly true that the association between 'natural' death and 'good' death is very old. Several historians have traced it back to early Modern history (Ariès 1981). Yet, neither historicity nor cultural tradition confers validity on a moral conception (e.g. Mill 1884). The question remains whether or not natural death really is the best way of dying.

When considering well-being at the end of life, various considerations need to be made, perhaps including the question of what best fits a cultural tradition. Other considerations include the weighing of the value of prolonging life against the suffering that might be experienced in the 'extra' lifespan, as well as the burden of end-of-life decisions on relatives. In our view, the primary concern should be to allow people a 'good' death, regardless of whether it is a 'natural' or an 'unnatural' death. Whether a 'natural' death should be regarded as intrinsically valuable is highly questionable in our view.

What is perceived as a 'good death' may vary greatly between different individuals. Some might consider it essential to die without pain or suffering. Others might prefer to die while remaining fully conscious for as long as possible, for example because they regard being able to communicate or having control and autonomy in the context of the

dying process as crucial (cf. The death of the Roman Emperor Hadrian, for example)[9]. For these people CDS could never be an acceptable option. Yet others might want to die in accordance with particular religious prescriptions.[10] For some people, furthermore, a 'good death' will be one where the dying process is 'steered' in a way that facilitates the coping of relatives to the greatest possible extent.

When considering care at the end of life, in our view the goal should be to try to ensure that a patient's death approximates as closely as possible her personal conception of a 'good death'. For patients who prefer a death that mimics a natural death, CDS may be the best option.

We need to advance the debate on CDS, since its proper use and moral acceptability are still topics of intense discussions. As we have tried to show, there are reasons to believe that the use of the term 'natural death' in relation to CDS seems to be part of an attempt to sanitize the practice (i.e. increase its ethical acceptability) and serves to provide a coping strategy for physicians and patients' relatives. However, we wish to emphasize that our criticism of the portrayal of death following CDS as 'natural' death and the ensuing justificatory strategy does not preclude the view that the use of CDS may be perfectly clinically *and* ethically justified in many cases. Several other principles have been proposed to justify CDS apart from its 'naturalness'. Furthermore, it is perfectly understandable that the various actors involved develop mechanisms to cope with

[9] See Birley (1997). In this book, the story of the death of the Roman emperor Hadrian is told. At the end of his life, Hadrian became very ill and wanted to commit suicide, which proved impossible since no one dared to provide Hadrian with a sword or poison, for fear of being executed afterwards. Hadrian finally persuaded Mastor, his hunting master, to help him, using threats and promises of riches and immunity. At the last moment, however, Mastor refused to help. Anthony, Hadrian's successor and the father of Marcus Aurelius, and the prefects received news of Hadrian's search for assistance in dying. When they asked Hadrian to bear his disease, he ordered the person who informed Anthony and the prefects to be executed. Anthony himself could have helped Hadrian, but, as an adopted son, assisting Hadrian would have required him to kill his own father. When Hadrian made another attempt to commit suicide, the knife he was planning to use was taken from him. When Hadrian asked his physician, Hermogenes, to provide him with poison, Hermogenes chose to take his own life rather than help Hadrian. Not receiving assistance in dying, Hadrian had to let his disease run its course until he finally passed away.

[10] For example, the Vatican's *Declaration on Euthanasia* notes: 'However, painkillers that cause unconsciousness need special consideration. For a person not only has to be able to satisfy his or her moral duties and family obligations; he or she also has to prepare himself or herself with full consciousness for meeting Christ. Thus Pius XII warns: "It is not right to deprive the dying person of consciousness without a serious reason".' (Sacred Congregation for the Doctrine of the Faith. May 5, 1980. *Declaration on Euthanasia*. quoted in Catholic Bishops' Conference of England and Wales. 2010. *A practical guide to the spiritual care for the dying person*, 32, available at http://www.catholic-ew.org.uk/Catholic-Church/Publications/Practical-Guide-to-the-Spiritual-Care-of-the-Dying-Person) [Accessed 13 July 2010].

difficult situations. Several of these mechanisms may even be considered as beneficial, for example the shared decision-making and the wish to supply the best death possible. Our main criticism is that the current discourse on sedation, in part as a result of the emphasis on 'naturalness', seems to lead to an increasing acceptance of CDS as a preferred end-of-life strategy and sometimes even as the only option.

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Chapter 5
Is continuous sedation at the end of life an ethically preferable alternative to physician-assisted suicide?

Updated version of a published journal article:

Raus, K., Sterckx, S. and Mortier, F. (2011) "Is Continuous Sedation at the End of Life an Ethically Preferable Alternative to Physician-Assisted Suicide?". *American Journal of Bioethics* 11(6):32–40.

5.1 Background

As stressed in the introduction of this dissertation, we live in a time when more and more people die in a hospital as a result of chronic disease (Cohen et al. 2007; van den Block et al. 2008) and many deaths are preceded by an 'end-of-life decision', understood here a medical decision (i.e. a decision by a physician or a nurse) that affects or is believed to affect the timing of death of the patient and/or the possibility of meaningful experiences by the patient (van der Heide et al. 2003; Bilsen et al. 2009; Seale 2009). The ethical acceptability of several types of end-of-life decision is intensely debated.

One of the most controversial end-of-life practices is 'physician-assisted suicide' (PAS). This involves a physician providing a patient, at her own request, with a lethal dose of medication, which the patient self-administers. It is clear that the ethical acceptability and the desirability of legalisation of this practice both continue to cause controversy.[1]

Although PAS is not the topic of this dissertation, the practice is often discussed together with the end-of-life practice that is the topic of this dissertation, namely continuous sedation at the end of life. It has also already been discussed that many types of continuous sedation exist and unlike the first chapter, this chapter will deal with continuous sedation that is light as well as with sedation that is deep. When relevant, reference will be made to continuous *deep* sedation (CDS), especially in reference to empirical data, since most available research data concern continuous *deep* sedation. When, therefore, empirical data are discussed in this chapter they will, unless mentioned otherwise, relate to 'continuous deep sedation'.

Sedation at the end of life has played an important part in two decisions of the US Supreme Court, *Vacco v. Quill (1997)* and *Washington v. Glucksberg (1997)*. These influential rulings, which are commented on below, dealt with the question of whether the US Constitution incorporated a right to assisted suicide. One of the concurring opinions explicitly mentioned what we call the '*argument of preferable alternative*': the argument that the availability of sedation makes allowing PAS unnecessary.

[1] Admittedly, the practice of euthanasia, which is not the subject of this chapter, is even more controversial.

This argument of preferable alternative is also encountered in academic literature. A good example is found in Arras (1998), who refers to CS in a comment on physician-assisted suicide:

> Finally, there are those few unfortunate patients who truly are beyond the pale of good palliative, hospice, and psychiatric care. The opponents of legalization must face up to this suffering remnant and attempt to offer creative and humane solutions. One possibility is for such patients to be rendered permanently unconscious by drugs until such time, presumably not a long time, as death finally claims them. (Arras 1998, 294)

In view of the important role of the argument of preferable alternative in the Supreme Court rulings, as well as in some of the academic literature on end-of-life decisions, and also in view of the increasing use of continuous sedation at the end of life (see below), our aim in this chapter is to critically assess the validity of this argument.

5.2 The argument of preferable alternative in two US Supreme Court Rulings

Vacco v. Quill and *Washington v. Glucksberg* are landmark decisions on the issue of PAS and a supposed Constitutional right to commit suicide with another's assistance. In *Washington v. Glucksberg*, the Supreme Court unanimously decided that, contrary to a Federal District Court ruling, upheld by the Court of Appeals for the 9th Circuit, the state of Washington's ban on PAS was not unconstitutional. The District Court followed the reasoning of three physicians who, with others, filed the suit. They had noted that while terminally ill patients on life support have a legal right to refuse all treatment (and thus effectively to end their lives), terminally ill patients who are not on life support lack this right. The District Court saw no relevant difference between withholding life-support from a terminally ill adult and competent patient, and assisting such a patient to end her life by supplying a lethal dose of medication.

In the Supreme Court rulings, the Justices attempt to show why they believe the US Constitution indeed includes a patient's right to refuse treatment, but *not* a right of physicians to help their patients to die. However, of the various arguments provided by the Justices, only one will be discussed in this chapter, namely the argument of preferable alternative.

In *Washington v. Glucksberg*, Justice O'Connor uses this argument explicitly in her concurring opinion. As to whether PAS should be legalized, she claims to 'see no need to reach that question' (Washington v. Glucksberg 1997, 736). The reason she gives is that in America:

> a patient who is suffering from a terminal illness and who is experiencing great pain has no legal barriers to obtaining medication, from qualified physicians, to alleviate that suffering, even to the point of causing unconsciousness and hastening death (Washington v. Glucksberg 1997, 736-737).

The Supreme Court did not rule on the acceptability of PAS because it was perceived as unnecessary to do so, which is in line with the Supreme Court tradition of never making a broad argument when a narrow one will suffice. However, the implications of Justice O'Connor's statement appear to be: (1) that CS is legally and ethically acceptable; and (2) that the mere availability of CS renders the legalisation of PAS unnecessary. Put differently, that CS is a preferable alternative to PAS.

Before proceeding to an analysis of various versions of this argument, it seems useful to give a brief overview of (the few) existing laws and guidelines regarding PAS and CS.

5.3 Regulations regarding PAS and CS

PAS

PAS involves a physician providing a patient with a lethal dose of medication, at her own request, which the patient then takes herself. This controversial practice is currently legal in only a few places, and the relevant laws differ in some respects.

Although the US Supreme Court ruled that a ban on PAS was not unconstitutional, this still left the door open for individual States to enact laws permitting PAS. Not long afterwards, Oregon adopted a law allowing PAS under certain conditions while still forbidding euthanasia (State of Oregon 1995). More recently, in 2008, Oregon's neighbour state Washington also enacted a law allowing PAS: the Washington Death with Dignity Act (State of Washington 2008).

The Netherlands[2] and Luxembourg[3] have laws legalising PAS as well as euthanasia. Belgium[4] has also legalised euthanasia, but has not explicitly legalised PAS, so its legal status there remains unclear.

The Swiss penal code prohibits killing on request (Art. 114), but assisting a suicide is punishable only if this is done for 'selfish reasons' (Art. 115).[5] This has enabled the establishment of several organisations that help patients commit suicide. Organisations such as 'Dignitas' and 'Exit' have internal guidelines as to who may rightfully claim assistance in dying. Exit, which was founded in 1982, *only* assists suicide for Swiss residents and stipulates certain conditions such as 'repeated request', and 'intolerable physical or psychological suffering' (Sobel 2003, 2). Dignitas, an organisation founded in 1998 which predominantly assists foreigners, requires that a patient must suffer from a 'fatal disease or unacceptable disability' (Griffiths et al. 2008, 471). The Swiss Academy of Medical Sciences argues that 'assisted suicide is not part of a doctor's task, because this contradicts the aims of medicine'.[6] However, a doctor's contribution to assisted suicide as a 'private person' is accepted by the Academy as a personal decision of conscience resulting from the specific doctor-patient relationship.[7]

In *Germany*, assisting a suicide is not prohibited. However, the German Medical Association prohibits physicians from assisting a suicide and, furthermore, every German citizen is required to help an unconscious person. This makes PAS difficult, but not impossible. The German Society for Dying in Dignity, for example, supplies its

[2] Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding. *Staatsblad* [Official Journal of The Netherlands]194, (2001) (effective 1 April 2002, *Staatsblad* 165, 2002).

[3] Loi du 16 mars 2009 sur l'euthanasie et l'assistance au suicide – A-N°46. *Journal Officiel du Grand-Duché de Luxembourg*, (2009), available at http://www.legilux.public.lu/leg/a/archives/2009/0046/a046.pdf.

[4] Wet van 28 mei 2002 betreffende de euthanasie. *Belgisch Staatsblad* [Official Journal of Belgium] (22 June 2002) effective 22 September 2002. Unofficial English translation available at http://www.kuleuven.be/cbmer/viewpic.php?LAN=E&TABLE=DOCS&ID=23.

[5] The modification of Art. 115 is currently a topic of heated debate in Switzerland. In October 2009 the Federal Council submitted two possible scenarios for consultation: (1) specifying strict duties of care to be respected by organizations that provide assistance; or (2) banning organized (as opposed to 'private' – see below) assisted suicide altogether.

[6] Swiss Academy of Medical Sciences (SAMS), Revised guidelines on care of patients at the end of life (2004). Presentation by Dr Margrit Leuthold, Member of the Swiss National Advisory Commission on Biomedical Ethics, at the 8th Global Summit of National Bioethics Advisory Bodies, Singapore, 26-27 July 2010.

[7] SAMS does specify the following conditions for such 'private' assisted suicides: the patient must be approaching the end of life; alternative ways of providing assistance must have been discussed and, if desired, implemented; and the patient must be a competent person expressing a persisting wish which has been carefully considered without external pressure.

members with information on how to obtain the drugs necessary for committing suicide (see for example Bundesärztekammer 2004; Bosshard et al. 2008).

Looking at these laws, one notices that a major underlying concern is to allow the patient to die in a 'dignified manner'. Not everyone can obtain assistance for suicide under these laws. The Oregon law as well as the laws of The Netherlands and Luxembourg require that the person concerned be a competent adult who suffers 'unbearably'. Moreover, in Oregon and Washington the patient must also be 'terminally ill' (implying that her remaining lifespan can be predicted).

To avoid a 'slippery slope', towards patients being coerced to ask for PAS and/or towards the involuntary killing of patients, several safeguards have been included in these laws. First, an assessment must be made of the patient's competence. Second, the patient has to repeat her request several times, to guarantee that it is enduring. In Oregon and Luxembourg, but not in The Netherlands, the patient must make a written request. A third important safeguard in all countries where PAS is legalized, is that an independent physician has to verify that the patient is indeed terminally ill (Oregon, Washington) or incurable and suffering unbearably (The Netherlands, Luxembourg).

Continuous sedation at the end of life

We now turn to the regulation of CS at the end of life, the practice whereby one administers sedatives resulting in the reduction or removal of a patient's consciousness until death follows. We are aware of three national guidelines relating to this practice: a guideline on sedation issued by the Royal Dutch Medical Association (KNMG) (KNMG 2009); a Guideline on sedation from the Norwegian Medical Association (NMA) (Norwegian Medical Association 2001); and certain passages within the code of ethics of the American Medical Association (AMA) (Levine 2008). These guidelines state that applying CS at the end of life should be a 'last resort' to be used only for dying patients with a very short life-expectancy and refractory symptoms. What the patient's life-expectancy should be, is stipulated only in the Dutch Guideline (less than 2 weeks).

Whether food and fluids should be continued to be administered or not is explicitly mentioned in the Dutch Guideline as well as in the NMA guideline. In the Dutch Guideline the withholding or withdrawing of food and fluids is encouraged. However, the NMA guideline clearly stipulates that if a patient was capable of taking in food and

fluids beforehand, then administration of food and fluids *should* be initiated together with the continuous sedation.[8] In practice, CS is frequently associated with the withholding or withdrawal of food and fluids (Miccinesi et al. 2006). Nevertheless, as shown in the previous chapter, CS is often claimed to 'allow the natural process of terminal disease to take place' (Levine 2008, 4), and to result in no (significant) shortening of life.[9] The intention or goal of CS, according to the abovementioned guidelines, must always be to relieve pain and suffering and never to shorten life.[10]

The guidelines on CS also differ in various respects. One example is that only the Guideline of the NMA requires that during the sedation 'raising the level of the patient´s consciousness must be considered and attempted' (Norwegian Medical Association 2001, point 9). If during the awakening process it becomes clear that consciousness is not in the patient's best interest, the patient must be sedated again. Another notable difference is that the AMA's Code of Medical Ethics states that a physician considering CS should consult with a multidisciplinary team, if available, including a physician with expertise in palliative care, to ensure that the symptom treatment is effective. The Dutch Guideline merely mentions that a physician has to consult with a colleague if she doubts her own expertise.

5.4 IS CS ethically preferable to PAS?

The argument that CS is ethically preferable to PAS, portrays sedation as morally unproblematic whereas PAS is regarded as clearly problematic or at least less problematic. Hence the question arises as to what, if anything, makes C(D)S[11] preferable to PAS. In order to answer that question, we will discuss and provide critical comments on four versions of the argument of preferable alternative that can be derived from the literature.

[8] Given that administering food and fluids to imminently dying patients can cause further medical problems, it seems unusual that this should be required.

[9] This claim has been discussed elsewhere in this dissertation.

[10] The issue of intention is, like the issue of life-shortening, very controversial and is the topic of chapter 4 of this dissertation on the application of the doctrine of double effect to CS

[11] We use the term C(D)S when a reference to continuous sedation at the end of life could apply to continuous sedation in general as well as to continuous *deep* sedation.

First version: 'The availability of sedation to eliminate pain and other symptoms implies that PAS need not be legalised'

As mentioned above, in the US Supreme Court decisions *Washington v. Glucksberg* and *Vacco v. Quill*, Justice O'Connor claimed that there was no need to address the question of legalization of PAS, as patients could legally obtain pain relief to the point of unconsciousness. One of the main advantages of C(D)S over PAS that follows from this line of reasoning is that C(D)S is legally permissible and widely accepted (for example by the American Medical Association in its code of ethics) whereas PAS is not.

Another pertinent example of this version of the argument can be found in a brief to the Supreme Court from the American Geriatrics Society (Lynn et al. 1997):

> [S]edation can always eliminate symptoms in persons near death. This course is available at present, without any change in the law, and thus precludes a requirement that the patient must have symptoms that cannot be relieved. While some may view such treatment as undesirable, it is difficult to see why death through PAS should be considered a distinctly better (and constitutionally dictated) policy option. (Lynn et al. 1997, 498)

Other commentators agree that the availability of CS makes a legalization of PAS *unnecessary* and go even further to claim that the existence of CS makes it *impossible* for any court to justify euthanasia or PAS. What is sometimes said to justify PAS and euthanasia is the legal doctrine of 'necessity', where a physician's duty to relieve pain and her duty to not shorten life conflict, and a physician has no other option to relieve pain than to shorten life. If CS forms a true alternative, the argument goes, it becomes difficult to invoke a defence of necessity for a physician who has intentionally shortened life. As Somerville argues:

> In extreme cases, pain relief can be achieved in ways that do not involve killing patients. Total sedation is one. This option makes it very unlikely that a court would hold that a defence of necessity would apply to justify euthanasia as a way of relieving pain. [...] In a few rare cases, when patients are receiving good palliative care, but all other measures to relieve pain or other symptoms of unbearable physical suffering have failed, total sedation could be the treatment of choice – one that is ethically and legally acceptable. (Somerville 2001, 130)

This line of reasoning, of course, is not a criticism of all legalisation of PAS, but merely against the invocation of the doctrine of necessity. Whether this doctrine can and should be used for legalising euthanasia is a matter for experts in law, although it is

clear that the doctrine has already been criticised as a sound legal justification for euthanasia and PAS (e.g. Otlowski 2000). Furthermore, it can be questioned whether CS and PAS truly are perfect alternatives. As we will explain below, a situation in which a patient requests PAS cannot always be properly addressed by offering sedation instead. In some cases, there may be good reasons why PAS would be preferable. Data from countries where both CS and PAS are legal give us an insight into the characteristics of both practices (e.g. the types of patients involved and the reasons for using the practice) which are relevant when assessing this version of the argument.

As to PAS, empirical research concerning Belgium and The Netherlands shows that this practice is rarely undertaken there. In these countries, patients who in other countries, where PAS is legal but not euthanasia, would probably choose PAS instead mostly ask for euthanasia. Research on euthanasia/PAS in The Netherlands and Belgium,[12] and on PAS in Oregon, shows that PAS (and euthanasia) are rarely used for very old patients (85+),[13] and occur more frequently among patients with a higher education. Furthermore, most patients in Oregon who choose PAS suffer from cancer – of all patients who died after PAS between 1998 and 2011, 80.9% suffered from cancer.[14] As regards the reasons patients gave for choosing physician-assisted suicide, these often included loss of autonomy, quality of life and dignity.[15] Pain and other bodily discomforts were only infrequently cited. In Oregon, for example, 'losing autonomy' was cited as a major concern in 90.9% of PAS cases, while 'inadequate pain control or concern about it' was mentioned in only 22.6% of the cases.[16]

Considering euthanasia patients, the same picture emerges. A recent study in The Netherlands by Rietjens and colleagues (2006) comparing C(D)S to Euthanasia found that the main reasons why people chose euthanasia were 'suffering without improving' (82%) and 'loss of dignity' (63%). Pain was considered an important reason for euthanasia in only 36% of cases. However, since multiple reasons could be mentioned by

[12] Even though the research reports combined data for euthanasia and PAS, we consider that there is likely to be little difference in the patient profile for PAS and euthanasia in The Netherlands and Belgium.

[13] Data from The Netherlands and Oregon show a slightly different picture. The official Oregon reports show that the practice mainly involves patients aged 65 to 85, while the majority of Dutch patients receiving euthanasia/PAS are younger than 65 (van der Heide et al. 2007).

[14] See table 1 of the official Oregon State report on the use of PAS, available at http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year14-tbl-1.pdf. [last accessed 20 November 2012].

[15] See for example Table 1 of the official Oregon State report on the use of PAS. See also Rietjens et al. (2006).

[16] See Table 1 of the official Oregon State report on the use of PAS.

respondents, the percentage of cases in which pain was the *sole* reason for requesting euthanasia was even lower.

The clinical image of C(D)S appears to be rather different from that of PAS. First, in Belgium and The Netherlands the available data clearly indicate that patients receiving CDS are usually older than patients receiving euthanasia or PAS. Second, while, as with euthanasia and PAS, CDS is mostly used on patients suffering from cancer, other diseases occur more frequently in patients receiving CDS. In The Netherlands, 88% of patients receiving euthanasia or PAS had cancer, for CDS this was 54%. The biggest difference between CDS and PAS, however, lies in the *reasons for initiating the practice*. Unlike PAS, CDS is usually initiated as a result of *physical* symptoms such as pain, nausea, vomiting and fatigue (Rietjens et al. 2008; Hasselaar et al. 2009). Many of the existing guidelines, such as a report by the American Medical Association, also recommend that the indication for CDS should be mostly a physical symptom (although some leave room for purely refractory suffering to be an indication). This issue will be dealt with more in depth in chapter 6.

We may conclude from these data that the practices of PAS and CDS differ in important respects. First, PAS and CDS seem to be applied to different groups of patients. PAS mainly occurs with terminally ill patients who value control and who feel that their disease has harmed or threatens to harm their dignity. They choose PAS not in order to avoid pain, but mainly because they want to avoid further indignity and they value the opportunity to control the manner in which they die. CDS, on the other hand, is used predominantly on patients who suffer physically. Patients who request CDS usually want to avoid pain and suffering.[17]

To conclude this section, the claim that in each case where PAS is requested by a patient, the situation can be properly addressed by offering sedation to the patient, is problematic. As illustrated above, sedation and PAS differ in important respects. Many patients who request PAS may not regard sedation as a suitable option, for this option makes control during the dying process impossible as it reduces or takes away the patient's consciousness. To claim that PAS and sedation are alternatives, in our view, shows a lack of appreciation of the different types of patients and their values and concomitant expectations regarding good end-of-life care and 'good death'. Hence, the

[17] It needs to be emphasised that, according to available research, *requests* for CDS rarely occur (e.g. Rietjens et al. 2004; Chambaere et al. 2010).

argument that PAS need not be legalised since sedation is legally available, is not a decisive argument.

Second version: 'Unlike sedation, PAS poses the risk of a slippery slope'

A second advantage CS might have over PAS is that it might be less susceptible to abuse. One of the main arguments against a legalization of PAS has always been the 'slippery slope'. Slippery slope arguments typically state that allowing something that seems good at first sight may in fact lead to allowing other practices we would not want to allow.

Such arguments are frequently applied in ethics as well as in lay reasoning (e.g. Hendin 1998; Jochemsen 1999). The Supreme Court decisions in *Vacco v. Quill* and *Washington v. Glucksberg* also include a slippery slope style of argument against legalising PAS.

Hence, if CS would not pose the risk of a slippery slope or if such risk would be significantly lower than for PAS, this would be an important moral reason for preferring CS over PAS. The validity of the slippery slope argument in the context that concerns us here has been widely debated and tested against empirical data. One of the claims of the argument is that a legalisation of PAS for terminally ill, competent patients would eventually lead to PAS being used in 'vulnerable groups'. It is argued that patients from certain categories such as elderly patients, patients from ethnic minorities, uninsured patients, and patients of a lower socio-economic status, would increasingly be pressured or coerced into asking for PAS. For example, in *Washington v. Glucksberg*, Chief Justice Rehnquist argued:

> The Court of Appeals dismissed the State's concern that disadvantaged persons might be pressured into physician assisted suicide as "ludicrous on its face." .... We have recognized, however, the real risk of subtle coercion and undue influence in end of life situations. (Washington v. Glucksberg 1997, 731-732)

The discussion on whether or not PAS is susceptible to a slippery slope is very complex. This is in part due to the fact that two different forms of slippery slope arguments must be distinguished: a logical form and an empirical form. The *logical* form of the slippery slope states that legalisation of PAS draws an arbitrary line to separate those who can and those who cannot receive PAS. Logic would then require us to continuously redraw this line until we are inevitably drawn to accepting assistance in suicide for nearly all patients. The *empirical* slippery slope states that the human psyche is such that allowing

doctors, even in a relatively small number of cases, to intentionally assist a person in ending her life, will inevitably lead to misuse and abuse.

For the purposes of this chapter, it is important to note that the concept of the slippery slope can be criticised both theoretically and empirically (e.g. van der Burg 1991; Lewis 2007). One example of a response to the argument that a legalisation of PAS would draw an arbitrary line, is that this is inevitable in legislation. Speed regulations are excellent examples of arbitrary boundaries. There is no notable difference between 30 mph and 31 mph, but logic has not forced us to continuously raise the urban speed limit. Another example is the regulation of drug use, where allowing the use of drugs such as caffeine and alcohol has not led to the deregulation of the use of cocaine and heroin.

As to the empirical form of the slippery slope, empirical data are sometimes used to support a slippery slope claim, but this is problematic. For the slippery slope argument to work, it must be shown that it is the legalisation itself and only the legalisation that has lead to a change in the incidence of a practice. In the Netherlands, for example, the adoption of the euthanasia law followed decades of public debate, supporting the hypothesis that the legalisation of euthanasia was a consequence of societal change rather than the cause of it.[18]

Whether the available data support a slippery slope claim with regard to PAS seems highly questionable. An important example of research using empirical data to investigate this claim is a study by Battin and colleagues (2007). They found that in both Oregon and The Netherlands there was no heightened risk to people in any vulnerable group.

Another relevant study is that of Chambaere et al. (2010), which provides detailed information regarding the practices of euthanasia, PAS and ending of life without request in Belgium. Most cases of ending of life without request occur among older patients, mostly with dementia. A comparison with all deaths nevertheless shows that these older patients are individually no more at risk than any patient in other groups of having their life ended without their request.

[18] Research by Norwood et al. (2009) paints an image of the euthanasia practice in The Netherlands that does not indicate slippery slope risks. As regards the indications of a slippery slope [with regard to the performance of euthanasia] in The Netherlands, Rietjens et al. (2009) have undertaken an extensive analysis of the data that is currently available. Their findings sketch an image of euthanasia that is more nuanced than the one usually drawn by those who posit a slippery slope.

Moreover, not only does it seem doubtful that PAS is likely to lead to abuse via a slippery slope, but it also seems questionable that CS is free from such a risk or even poses a considerably lower risk. In the C(D)S guidelines discussed above, the practice is recommended only as a 'last resort', but available data regarding the incidence of CDS in The Netherlands, Belgium and the UK show that this practice is applied frequently and that its incidence is growing rapidly. In Belgium, for example, CDS accounted for 8.2% of all deaths in 2001, while by 2007 this had risen to 14.5% (Bilsen et al. 2009). Data from The Netherlands also indicate a rising incidence (Rietjens et al. 2008). Note, also, that this only concerns sedation at the end of life that was *deep,* so that the total incidence of continuous sedation (regardless of depth) is even higher. Furthermore, available research documents some characteristics of the application of CDS that make it questionable whether this practice is in fact not susceptible to abuse. A recent study by Chambaere and colleagues, for example, shows that in 80% of CDS cases in Belgium neither the patients nor the family either consented to or requested the practice (Chambaere et al. 2010). Physicians taking part in this study also indicated that in 13% of CDS cases they had a co-intention of hastening the patient's death and in 4% of cases they even indicated an explicit intention of hastening death. What these findings suggest is that, viewed from the perspective of the guidelines mentioned above, at least *deep* continuous sedation is clearly susceptible to abuse.[19]

Our conclusion regarding the second version of the argument of preferable alternative must therefore be that it is doubtful that C(D)S is less susceptible to abuse than PAS. First, data from places where PAS is legal do not indicate the existence of a slippery slope. Second, even if legalising PAS *would* lead to a slippery slope, available research indicates that it is not at all certain that C(D)S would avoid this risk. Whatever the validity of slippery slope arguments, it turns out that C(D)S and PAS cannot be distinguished on the grounds of susceptibility or non-susceptibility to abuse. Thus the second version of the argument, like the first, is unconvincing.

Third version: 'Unlike PAS, sedation is consistent with the physician's role as a healer

Another important reason why C(D)S is considered by some as morally superior to PAS is that the practice of C(D)S is regarded as being in line with the physician's duties and with her 'role as a healer' (Levine 2008, 1). This claim can for example be found in the

[19] In this article we cannot undertake a critical normative assessment of these guidelines, so by 'abuse' we mean here 'failure to comply with the guidelines' rather than abuse in a purely ethical sense.

Dutch national guideline on sedation, which explicitly mentions that, unlike euthanasia, CS is 'normal medical practice' (KNMG 2009, 6). The underlying assumption is that practices which can be regarded as 'normal medical practices' automatically fall within the boundaries of the role of the physician.

The concept of 'normal medical practice' has both a factual/legal and a normative side. The '*factual*' side concerns the issue as to whether a particular practice is labelled as 'normal medical practice' in (medical) law and/or professional/deontological codes. John Griffiths, who has written extensively on legal aspects of end-of-life decisions, defines 'normal medical practice' as 'behavior that doctors are generally authorized to perform based on medical indications and according to professional (technical and ethical) norms' (Griffiths et al. 1998, 91). In the Dutch system, when an action is deemed 'normal medical practice' it falls under the 'medical exception' to certain criminal offences in the law. A patient who dies during open heart surgery, for example, is considered to have died a 'natural death' so no official investigation of the death will be undertaken. The *normative* side of the term implies that using the label 'normal medical practice' conveys a message of moral acceptability. In the context of our discussion, we are mainly interested in this normative side.

The claim that, unlike PAS, sedation is consistent with the physician's role as a healer, implies that, when two possible responses to a patient's suffering are possible, one *must* choose the option that ties in with the role commonly associated with the physician. Indeed, relieving pain is usually regarded as an important element of a physician's role. The following statement by Orr (2001) illustrates this argument:

> [Physician-assisted suicide and euthanasia] have been outside *the bounds of acceptable behavior for physicians* for hundreds of years. The morally, legally, and *professionally acceptable alternative* is excellent end-of-life care. Because pain (and fear of pain) at the end of life is one of the driving forces behind the recurrent debate about legalization of [physician-assisted suicide and euthanasia], the medical profession as a whole, and pain specialists in particular, have an obligation to use all available means to relieve pain. (Orr 2001, 136)

Obviously, pain can be relieved in several ways. Some might even regard PAS as a way of relieving pain, but according to Orr and many others it is not the 'right' way to achieve that goal, whereas sedation is. As Lo and Rubenfeld put it:

> Although palliative sedation should never be easy for caregivers, it is immensely rewarding to relieve a dying patient's suffering, without crossing the line into ethically controversial ground. (Lo and Rubenfeld 2005, 1815)

This idea that PAS is incompatible with the role of the physician as a healer is also mentioned in the Supreme Court ruling in *Washington v. Glucksberg*. Chief Justice Rehnquist, who delivered the opinion for the Court, refers to the Code of Ethics of the American Medical Association: 'Physician-assisted suicide is fundamentally incompatible with the physician's role as healer' (Washington v. Glucksberg 1997, 731, referring to Council on Ethical and Judicial Affairs, 1993). Moreover, Rehnquist also notes that:

> [P]hysician assisted suicide could [...] undermine the trust that is essential to the doctor-patient relationship by blurring the time honored line between healing and harming. (Washington v. Glucksberg 1997, 731)

How convincing is this view? As we argue below, C(D)S is not about healing. Hence, those who regard sedation as falling within the role of the physician cannot argue that C(D)S can be distinguished from PAS on the basis that this one is a healing act and the other is not.

It seems worth noting that even in *Washington v. Glucksberg* the view that PAS would harm the physician-patient relationship is questioned by Justice Stevens, who writes the following in his concurring opinion:

> A doctor's refusal to hasten death "may be experienced by the [dying] patient as an abandonment, a rejection, or an expression of inappropriate paternalistic authority". For doctors who have long standing relationships with their patients, who have given their patients advice on alternative treatments, who are attentive to their patient's individualized need, and who are knowledgeable about pain symptom management and palliative care options, [...] heeding a patient's desire to assist in her suicide would not serve to harm the physician patient relationship. (Washington v. Glucksberg 1997, 748, quoting from Block and Billings 1994, 2045)

Stevens' observations are supported by empirical research conducted in the US, indicating that only 20% of respondents agreed that they would trust their doctor less if 'euthanasia were legal [and] doctors were allowed to help patients die' (Hall et al. 2005, 694).[20] Indeed, to the extent that *a priori refusing* a request for PAS would undermine a

[20] Note here that it is to be expected that legalizing euthanasia would pose a greater risk of undermining patients' trust in their doctor than legalizing PAS, for in the case of euthanasia the doctor and not the patient performs the life-ending act.

patient's trust in her physician, such refusal would pose a risk of harming the physician-patient relationship.

Furthermore, recent data from physician surveys give us additional reasons to doubt the accuracy of the image of the role of physicians as being limited to 'healing'. Research shows that in a large number of countries (not just those that have legalized PAS or euthanasia) doctors make decisions and perform actions that may shorten the life of patients. Moreover, the life-shortening effect is not infrequently intentional (see e.g. Emanuel 2002; Sprung et al. 2003; van der Heide et al. 2003; Cohen et al. 2007.) As regards CS in particular, data from Belgium and The Netherlands show that doctors often report a co-intention or an explicit intention to shorten life, when using CS. (Rietjens et al. 2008; Chambaere et al. 2010)

To conclude this section, we would stress that, like PAS, C(D)S is *not* about healing. 'Healing' symptoms means 'taking the symptoms away'. In this sense, a headache is healed when effective analgesics are taken and the headache disappears. But C(D)S is a last resort option when 'healing', in this sense, is no longer possible. When, for example, the European Association for Palliative Care's Ethics Taskforce in its statement on euthanasia and PAS, says that '[t]he use of heavy sedation (which leads to the patient becoming unconscious) may sometimes be necessary to achieve identified therapeutic goals' (Materstvedt et al. 2003, 100), it is using the term 'therapy' in a very odd way. C(D)S takes away not just specific symptoms, but *any* kind of pain and discomfort, by diminishing consciousness. *Deep* sedation even suppresses the possibility of any kind of experience, including positive ones that do not require 'therapy'. It is a 'therapy' that takes away the basis of experience itself. In that sense, going into an irreversible coma also constitutes a 'therapy' for unbearable symptoms, just as dissolving in the air and disappearing from the earth would do. So either C(D)S is not a therapy at all, or if it is, so is PAS, which is explicitly intended to achieve a state of permanent and irreversible unconsciousness. The way in which CDS and PAS 'treat' symptoms is very much the same: by taking away consciousness. Thus, this version of the argument of preferable alternative also fails to convince.

Finally, let us move to briefly considering the fourth and last version of the argument we wish to investigate.

Fourth version: 'CDS is a 'third way' or compromise'

According to some commentators, CDS can function as a compromise or 'third way' in the debate about legalizing PAS (and/or euthanasia). Timothy Quill and Ira Byock (2000), for example, describe one of the main advantages that CDS has over PAS as follows:

> [CDS allows] clinicians to address a much wider range of intractable end-of-life suffering than physician-assisted suicide (even if it were legal) and can also provide alternatives for patients, families, and clinicians who are morally opposed to physician-assisted suicide (Quill and Byock 2000, 408).

The same idea is supported by ethicist Torbjörn Tännsjö who sees CDS as a way to sidestep the debates surrounding PAS and euthanasia where a stalemate is reached and neither side is ready to give in (Tännsjö 2004, 29). Interestingly, this view is not unusual among medical practitioners (Seymour et al. 2007, 1687).

This view, however, is also highly problematic, for reasons that we have discussed earlier. First, we would agree with the commentators who claim that CS is a bad compromise between proponents and opponents of PAS and euthanasia. Battin, for example, remarks that: 'it is not a real down-the-middle compromise. It sells out on most of the things that may be important—to both sides' (Battin 2008, 27). As argued earlier, we do not agree that C(D)S constitutes a real alternative to PAS in practice, so it should not be presented as a compromise alternative. For patients wanting PAS, closing off that option will frequently mean having to choose between two ways of dying which they may consider to lack dignity: in unbearable pain or without consciousness.

Second, and more importantly, we believe that the idea that CS is, intrinsically, ethically preferable to PAS is false. Earlier on we have tried to show why, in our view, there are reasons for doubting the common image that whereas CS is unproblematic PAS is morally undesirable. CS has its own associated moral controversies (even though there seems to be a tendency to brush these under the carpet) and is an unsuitable candidate for a compromise option or for an *a priori* preferable alternative in end-of-life decision-making. Thus, this version of the argument is also unpersuasive.

5.5 Concluding remarks

Whether CS, as an end-of-life practice, is morally preferable to PAS is an important question. Although CS is a relatively new practice, it has rapidly gained widespread acceptance and so it, unlike PAS, is seen by many as an end-of-life decision that poses little or no moral difficulties.

However, the argument of preferable alternative, in the different versions in which it is made by various academics, clinical practitioners and policymakers, turns out to be unconvincing. The claims we have investigated in this chapter purport to provide reasons why CS is *in itself* (i.e. by definition) preferable to PAS. None of these claims, however, seems to survive scrutiny.

Of course this does not rule out the possibility that there might be cases where CS is in fact an ethically preferable alternative to PAS or even to any other possible end-of-life practice. With regard to the debate on the legalisation of PAS, however, the availability of CS is not a decisive argument against legalisation of PAS. CS should not be presented as a 'third way' that allows the debate on whether or not PAS should be made legal to be 'resolved' or sidestepped.

CS and PAS differ in important empirical and ethical respects. Some patients might prefer PAS at the end of life, while other patients might have good reasons to prefer CS. We realise that those who oppose PAS on principle will not be convinced by any of the arguments we have made in this chapter, but we believe that in some cases PAS may constitute a proper response to unbearable suffering at the end of life. Our main conclusion therefore is that CS should not be seen as an ethically preferable alternative to PAS or as the preferred end-of-life practice *tout court*, but as a practice that may be ethically acceptable in some cases, just as other options such as, for example, non-treatment decisions and physician-assisted suicide, may be acceptable in other cases.

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Chapter 6
Can the Doctrine of Double Effect justify continuous deep sedation at the end of life?

Forthcoming as book chapter:

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6.1 Introduction

The doctrine of double effect (DDE) plays a very influential role in medical ethics as well as in clinical practice (Beauchamp & Childress 1994) and it is very frequently invoked as a justification for several practices and decisions at the end of life. For example, both non-treatment decisions and decisions to administer pain-relieving drugs with a possible life-shortening effect are considered by many to be justified by DDE. Moreover, DDE also sharply distinguishes these practices from practices such as physician-assisted suicide and euthanasia, which, according to DDE, are unjustified and therefore impermissible.

For the purposes of this chapter, we will focus on another end of life decision, namely continuous deep sedation at the end of life (CDS), the practice whereby a doctor significantly reduces or takes away a patient's consciousness until death follows. Several commentators consider CDS to be more like non-treatment decisions or the alleviation of pain and symptoms than like euthanasia and physician-assisted suicide, and thus to be justified according to DDE (Boyle 2004; Cavanaugh 2006). Arguably, the doctrine of double effect even serves as one of the main legal justifications of CDS in some jurisdictions, as can for example be seen by a statement from the US Supreme Court in the case of *Vacco v. Quill*, one of the most influential US Supreme Court rulings on end of life decisions, where the Court stated that: '[a]lthough proponents of physician-assisted suicide and euthanasia contend that terminal sedation is covert physician-assisted suicide or euthanasia, the concept of sedating pharmacotherapy is based on informed consent and the principle of double effect' (*Vacco v. Quill* 1997, 807).

In this chapter, we will investigate whether DDE can in fact be unproblematically invoked to justify continuous deep sedation. Since we will discuss the application of DDE, its history is not particularly relevant to the purposes of this chapter. Nonetheless, its many uses in the past (e.g. as a mere casuistic principle, an intuitively valid moral guideline, a paradigm of a full ethical theory, etc.) do indicate that there is considerable difference of opinion over the implications of DDE for moral conduct.

6.2 Different interpretations of DDE

As mentioned above, no single agreed upon interpretation of DDE exists, and thus there are relevant differences among those who accept the doctrine. What is agreed upon is the function of DDE. DDE was originally introduced as a solution to an action problem, where an agent wishes to do good (follow a right rule), but cannot do so without causing some harm.[1] DDE solves this problem by stating that an agent may cause harm as a side-effect, provided that this harm is unintentional and that the intention is to do good. Thus, applying DDE to complex and concrete ethical cases (such as end of life decisions) serves its proper function. As, for example, Joseph Mangan argues: '[The doctrine of double effect] is not an inflexible rule or mathematical formula, but rather an efficient guide to prudent moral judgment in solving the more difficult cases' (Mangan 1949, 41).

What is the subject of debate, is the question as to what theoretical moral framework DDE belongs to, or, as Joseph Boyle puts it: 'who is entitled to double effect?' (Boyle 1991, 475). According to some commentators, DDE is essentially a *theoretical construction* that is closely tied to an absolutist deontological framework and functions to make that framework coherent (Duff 1976). Oderberg, for example, argues that DDE forms 'one of the indispensible planks of any moral system worthy of serious consideration' (Oderberg 2004, 211). Others consider it to be a *practical tool* or way of reasoning that allows practical problems to be dealt with (Boyle 2004; Cavanaugh 2006), and as such not dependent on any specific moral theory. Joseph Boyle, for example, notes that: '[t]he logic of double effect (...) has application in medical ethics and the law, quite independently of the particular moral framework in which it was developed and has a natural function in moral reasoning' (Boyle 2004, 59).

It is possible to roughly distinguish three groups among those who use and defend DDE. The first group, the largest one, includes those thinkers who adhere to the classical interpretation of DDE and situate themselves within the natural law tradition.[2] Thinkers in this group include Mangan, Anscombe, Boyle, and Sulmasy, all of whom are discussed below. More often than not, when DDE is invoked to justify CDS, an interpretation belonging to the natural law family of interpretations of DDE is used.

[1] DDE was, historically, invoked by Thomas Aquinas as a justification for some forms of self-defence, where an agent wants to protect her own life but cannot do so without causing harm to her assailant.
[2] This is not surprising since DDE originated within the Roman Catholic moral tradition.

The second group includes thinkers who are sympathetic to DDE, but situate themselves outside the natural law tradition (e.g. Phillipa Foot and Warren Quinn). Quinn's interpretation is highly influential, but he describes DDE in such a way that it is inapplicable to end of life issues Quinn (1993). For Quinn, DDE distinguishes between two types of agency - *direct* agency and *indirect* agency. In *direct* agency an agent deliberately infringes on a victim's rights to further her own plans, while in *indirect* agency an agent infringes a victim's rights, but this infringement is in no way essential to the aim the agent wishes to achieve. Thus, according to Quinn: 'we need, ceteris paribus, a stronger case to justify harmful direct agency than to justify equally harmful indirect agency' (Quinn 1993, 184-5).

In Quinn's interpretation, DDE applies only to cases where one (or more) person(s) is being harmed and one (or more) different person(s) is being benefited. Since the person being benefited cannot be the same as the one being harmed, Quinn's interpretation of DDE excludes *intra*personal dilemmas and applies only to *inter*personal dilemmas (e.g. abortion or self-defence). This interpretation then does not apply to continuous deep sedation since, in this case, the patient receiving sedation is the one person being both harmed and benefited.

Finally there are also thinkers who are, arguably, revisionist in their interpretation of DDE, namely the proportionalists (discussed below). Distinguishing between these three groups is important, for in this chapter we will mainly discuss the application of the classical (i.e. natural law) interpretation of DDE to CDS, so our comments need not necessarily apply to *all* interpretations and revisions of DDE.

The classical formulation

As a theoretical concept, DDE has known many different formulations. One of the classical formulations has been set out as follows by Joseph Mangan:

> [A] person may licitly perform an action that he foresees will produce a good and a bad effect provided that four conditions are verified at one and the same time:
> (1) That the action in itself from its very object be good or at least indifferent
> (2) That the good effect and not the evil effect be intended
> (3) That the good effect be not produced by means of the evil effect; and
> (4) That there be a proportionally grave reason for permitting the evil effect. (Mangan 1949, 43)

In view of the first condition, this formulation of DDE assumes that some actions are absolutely good (i.e. good in themselves), and that others are absolutely bad (i.e. bad in

themselves). Which acts are absolutely right, which are absolutely wrong, and which are merely relatively right or wrong, cannot be determined by DDE itself but depends upon other principles or reasons. This is why many commentators claim that DDE requires a deontological framework in order to function properly and only makes sense as one of a number of principles.

DDE deals with relative wrongs, i.e. its application is limited to actions that are not clearly and absolutely wrong. If such an action has both a good and a bad effect and satisfies the four conditions mentioned above, then, according to this formulation of DDE, it is *permitted*. It should be noted that DDE only permits certain actions, but in no way confers an obligation to act; one may always choose not to perform an action that is permitted by DDE (Spielthenner 2008). Actions that do not satisfy these four conditions are considered unjustified and thus *impermissible*.[3]

A good example of a debate in which DDE has played a very influential role, is that concerning abortion (Connery 1977). If one considers an embryo or foetus to be a person (or at least a potential person) it would seem that all types of abortion are forbidden on the ground that it is always wrong to kill a person. Applying DDE, however, allows one to maintain the general rule against killing, while still allowing some forms of *therapeutic* abortion (i. e. abortion to remove a serious health threat to the mother).

A case to which the classical formulation of DDE applies is the so-called Hysterectomy Case: suppose that a woman in the early months of pregnancy is discovered to have cancer of the uterus and a hysterectomy is required to save her life. When applying Mangan's formulation, this action is allowed if and only if:

1) When a woman suffers from a cancerous uterus, a hysterectomy *in itself* is good or at least neutral.[4] Since a hysterectomy is neutral in this case, condition (1) is fulfilled.

[3] Thus one could say that DDE has more strength as a *prohibitive* principle than as a *permissive* principle.

[4] It is clear that, without qualification, a hysterectomy is not in itself neutral since it involves exposing a body to significant risks. What justifies hysterectomy in the case of a woman with a cancerous uterus is the principle of totality, which states that one part of the body may be harmed for the sake of the health of the whole body. As noted earlier, classical DDE functions only in combination with other principles. These principles are here taken to justify the hysterectomy before DDE is applied. DDE is then 'brought in' to morally assess the additional complication that the woman needing the hysterectomy is carrying a foetus in her womb.

2) The good effect is the saving of the mother's life, while the bad effect is the death of the early foetus (the 'unborn child'). If the physician does not intend to kill the foetus, but rather intends only to save the mother's life, condition (2) is fulfilled.

3) In this case the mother's life is saved by the removal of the uterus and not by the death of the unborn child. Hence condition (3) is also fulfilled.

4) Arguably, saving the mother's life is a proportionally grave reason for allowing the death of the unborn child, so condition (4) is also fulfilled.

Since all the conditions seem to be fulfilled, then, according to DDE, the hysterectomy may legitimately be performed.

This case is often contrasted with the so-called Craniotomy Case, which involves a controversial procedure that was first discussed by Catholic moralist thinkers in the nineteenth century (Connery 1977), and has been discussed extensively, for example by H.L.A. Hart (1986). In this case, described as follows by Marquis: '[T]he head of an unborn child is lodged in its mother's birth canal. Suppose that the head cannot be dislodged without crushing the baby's skull. Suppose that if the child is not dislodged, the mother will die' (Marquis 1991, 518).

At first sight, the Craniotomy Case is similar to the Hysterectomy Case in that there is both a good and a bad effect. When applying the four conditions, however, the differences become apparent. First, it is clear that crushing the unborn child's skull is not in itself good or neutral (condition (1) is not met). Furthermore, since one cannot crush the unborn child's skull without killing her, the good effect of saving the mother is obtained through the evil effect, thereby clearly violating condition (3). In this case it is impossible to produce the good effect without the bad effect, so one has to *intend* the bad effect, thereby violating condition (2). What about condition (4)? Arguably, saving the mother's life is a proportionally serious reason to allow the unborn child to die. Setting aside the problem that 'killing' may have a different impact on proportionality than 'allowing to die' (the former making the death of the unborn child worse than the latter), it might be conjectured that the proportionality requirement is satisfied. Overall then, the Craniotomy Case fails to fulfill three out of four of the conditions and thus, according to the classical formulation of DDE, is unjustified.

The classical formulation of DDE, which is referred to in many articles and textbooks, has been criticised for having certain problems. As a result, several other formulations

of DDE have been proposed. Before looking into these, we will first discuss the 'redescription problem' since this will become relevant later on in this chapter.

The redescription problem

As shown above, classical DDE relies strongly on what one's intentions are, versus what one brings about as a 'side-effect'. One of the most important commentators in this respect is Elisabeth Anscombe, who attempted to find a good criterion for intention and closeness in her book *Intention.* She acknowledges that a major problem in determining one's intention is that 'a single action can have many different descriptions' (Anscombe 1958, 11). One of the examples she uses is of a person sawing a plank, an action that could be described as 'sawing a plank', or 'sawing oak', or 'sawing one of Smith's planks'. These are all descriptions of the same action but are not all necessarily performed intentionally by the person sawing the plank. She might, for example, not realise that the plank is made of oak or that it is one of Smith's planks and she can therefore not be said to intentionally saw oak or one of Smith's planks.

However, *knowledge of* what one is doing does not suffice for establishing intentionality according to Anscombe. The person sawing the plank might, for example, saw planks for a living and thus only have the intention to do her job. What you intend to do must in some way also provide the *motivation* or *reason* for you to act the way you do. One's intention in acting then is the answer one would give to the question: 'Why are you doing what you are doing?'. The answer might, for example, be: 'to do my job', or 'to help Smith by sawing one of her planks', thereby establishing the intention. Also, because Anscombe believes that intention is not something that is purely inside the agent's head, one's actions must be in accordance with the answer one gives to the 'Why?' question, thereby making intention a bit more objective. As an example, Anscombe asks us to '[c]onsider the question "Why are you going upstairs?" answered by, "To get my camera"' (Anscombe 1958, 35). Now if one would answer 'But your camera is right here' and the other person were to respond: 'I know but I'm still going upstairs to get it', one might question this person's self-claimed intention in going upstairs.

When related back to the Craniotomy Case, this would mean that we could ask the physician 'Why did you crush the baby's skull?', to which the physician might respond: 'To be able to remove the baby from the birth canal and thereby save the mother's life'. In this case, although 'killing the baby' would be a correct description of the physician's action, it is not, as such, intended because it does not provide the reason for the

physician's action.[5] The downside, however, is that this makes the intention of an action depend strongly on what the agent says her reason for acting was.

The problem of redescribing intentions in classical DDE was also acknowledged by Philippa Foot, who has discussed DDE from outside the natural law tradition. She pointed out that there is a problem with condition (1), namely that the action must in itself be good or at least neutral (Foot 1978). The problem is that DDE makes a distinction between a good or neutral action and the effects it brings about, thereby allowing that every action can be redescribed to fit this action structure. In the Craniotomy Case, for example, one might say that the physician merely intends to reduce the size of the unborn child's skull with the bad side-effect that the unborn child dies and the good side-effect that the mother survives. The death of the unborn child can then be said to be unintentional in the sense that the death of the unborn child was not the reason for performing the craniotomy (cf. Anscombe's interpretation of intention). When redescribed like this, the Craniotomy Case fits DDE. However, this redescription can be applied in almost any case, making almost every case fit DDE, thereby making it a catch-all principle. The only way to solve this, would be to formulate some sort of 'criterion of closeness', linking intended actions to their closely related side-effects so that they are inseparable from the action. Foot, however, concluded that no proposal would actually solve the redescription problem.

Joseph Boyle, in an influential contribution to the debate, acknowledged that the classical formulation of DDE falls victim to the redescription problem, and made an attempt to solve this problem *within* the classical (natural law) interpretation of DDE. He accepted the impossibility of formulating a 'closeness criterion' and proposed to focus on the intentional structure of actions:

> On this conception, one intends one's ends, the state of affairs one aims to achieve in action, and one also intends one's means, that is the precise steps one takes to achieve one's ends. Features of one's voluntary actions which are not one's ends or means are side effects. Side effects are consequences or other aspects of one's actions which are neither the goal one seeks in acting nor the precise state of affairs one is committed to realizing for the sake of these goals. (Boyle 1991, 479)

So instead of focussing on actions and the effects they bring about, Boyle focuses DDE on the state of affairs one is committed to bring about. The replacement of 'actions' by a

[5] Even though the physician might be aware of the fact that her action necessarily causes the baby's death.

language emphasizing intended versus foreseen states of affairs results in a two-condition formulation of DDE:

> The double effect doctrine states that such harms [i.e. of the kind involved in DDE-cases] may be brought about if two conditions are met:
> (1) the harms are not intended but brought about as side effects; and
> (2) there are sufficiently serious moral reasons for doing what brings about such harms. (Boyle 1991, 476)

This alternative formulation led Boyle to treat certain cases differently as compared with Mangan's 'classical' formulation. The Craniotomy Case, for instance, is a genuine case of valid DDE reasoning for Boyle, because the physician is only committed to realising a state of affairs in which the mother is saved. The death of the unborn child is in no way essential to the state of affairs the physician is committed to. This shows how theoretical disagreements about the proper formulation of DDE can result in a different evaluation of particular ethical dilemmas.

Proportionalism

As mentioned earlier, a revised form of DDE reasoning is advocated by an increasing number of thinkers. One of these revised interpretations is known as 'proportionalism'. This interpretation of DDE is controversial, as shown by the fact that the former Pope, the late John Paul II, compared proportionalism to consequentialism and condemned both in his Encyclical Letter *Veritatis Splendor* (Pope John Paul II 1993).[6]

[6] The Pope noted that, with regard to the problem of the 'sources of morality' (the question on what the moral assessment of man's free acts depends), 'there have emerged in the last few decades new or newly-revived theological and cultural trends which call for careful discernment on the part of the Church's Magisterium'. (Pope John Paul II 1993, 74)
With regard to consequentialism, he stated that this theory 'claims to draw the criteria of the rightness of a given way of acting solely from a calculation of foreseeable consequences deriving from a given choice'. Proportionalism, according to him, 'by weighing the various values and goods being sought, focuses rather on the proportion acknowledged between the good and bad effects of that choice, with a view to the "greater good" or "lesser evil" actually possible in a particular situation'. (Pope John Paul II, 75)
He stated: 'Such theories however are not faithful to the Church's teaching, when they believe they can justify, as morally good, deliberate choices of kinds of behavior contrary to the commandments of the divine and natural law. These theories cannot claim to be grounded in the Catholic moral tradition. Although the latter did witness the development of a casuistry which tried to assess the best ways to achieve the good in certain concrete situations, it is nonetheless true that this casuistry concerned only cases in which the law was uncertain, and thus the absolute validity of negative moral precepts, which oblige without exception, was not called into question'. (Pope John Paul II 1993, 76)

Proponents of this reading of double effect ('proportionalists') consider the classical interpretation of DDE to be problematic in view of its reliance on an erroneous view of causality and intention (Kaczor 1998; Kalbian 2002). For Peter Knauer, arguably the first proportionalist, intention cannot be seen as being detached from proportionality. In a self-defence case, for example, I can only claim to intend to defend myself if the violence I use is proportional to the goal of defending myself. Thus, if I use a disproportional level of violence, I cannot claim that my intention was merely to defend myself. Knauer argued that:

> The purely physical series of events is irrelevant to the moral qualification of good or bad. (...) If there is a commensurate reason for the permitting or causing of the evil, the means is effectively willed only in its good aspect. (Knauer 1967, 149)

Proportionalism thus distinguishes between a *psychological* intention and a *moral* intention; even when a person *psychologically* intends (i.e. wilfully brings about) a certain action, when there is a grave reason for performing that action she does not necessarily *morally* intend that action. Thus, according to proportionalists, any action that has both good and bad effects may rightfully be performed if the good effect is proportionate to the bad effect. This allows proportionalism to escape the criticism of redescription, but quite possibly at the cost of allowing too much, since according to proportionalism every evil can be rightfully caused or allowed to happen, as long as there is a proportionate reason for doing so.

Proportionalism will not be discussed further in this chapter, since the proportionalist interpretation of DDE is often so different from the classical interpretation that addressing the distinction between the two would merit a chapter of its own. Indeed, many proportionalist thinkers are very critical of the classical formulation of DDE. A good example is Joseph Selling, who argues that DDE has been overextended and that its application has become so common, that it has trumped moral thinking. He argues that amending DDE so as to fit any moral question regarding what is permitted, is unnecessary and instead advocates a revision of the methodology of ethics so that the

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The reason for the fundamental incompatibility of these theories with the Catholic moral tradition is of course that, according to that tradition, certain kinds of behavior are intrinsically evil. As explained by the former Pope: '[T]he consideration of ... consequences, and also of intentions, is not sufficient for judging the moral quality of a concrete choice. The weighing of the goods and evils foreseeable as the consequence of an action is not an adequate method for determining whether the choice of that concrete kind of behaviour is "according to its species", or "in itself", morally good or bad, licit or illicit. The foreseeable consequences are part of those circumstances of the act, which, while capable of lessening the gravity of an evil act, nonetheless cannot alter its moral species'. (Pope John Paul II 1993, 77)

essentially limited scope of DDE (and of other principles) may be replaced by a comprehensive system of moral principles.[7](Selling 1980)

Let us now turn to the application of DDE to end of life practices, and to CDS in particular.

6.3 DDE and end of life practices

The Standard Vatican Case

The classical example of applying DDE to end of life practices concerns the administration of drugs to a terminally ill patient with the intention of preventing, lessening or taking way the patient's suffering, with the foreseen but unintended side-effect of life-shortening. Let us call this the *Standard Vatican Case*, as the applicability of DDE to it is clearly formulated in the Declaration on Euthanasia (1980) issued by the Vatican's Sacred Congregation for the Doctrine of the Faith:

> At this point it is fitting to recall a declaration by Pius XII, which retains its full force; in answer to a group of doctors who had put the question: "Is the suppression of pain and consciousness by the use of narcotics ... permitted by religion and morality to the doctor and the patient (even at the approach of death and if one foresees that the use of narcotics will shorten life)?" the Pope said: "If no other means exist, and if, in the given circumstances, this does not prevent the carrying out of other religious and moral duties: Yes." In this case, of course, death is in no way intended or sought, even if the risk of it is reasonably taken; the intention is simply to relieve pain effectively, using for this purpose painkillers available to medicine (Sacred Congregation for the Doctrine of the Faith 1980, Section III).

This case clearly falls under the classical formulation of DDE where the action of administering pain-relieving drugs has the good intended-effect of relieving suffering and the bad side-effect of hastening death.

[7] In his opinion DDE '*may*' (his emphasis) function at the level of concrete moral decision making, but it has 'absolutely nothing' to do with an overall 'objective' level of making moral statements (Selling 1980, 56-7).

Questions concerning the application of DDE to end of life cases

Although it is clear that DDE is invoked to justify certain end of life practices, for example in the Standard Vatican Case, some concerns about the applicability of the doctrine to end of life scenarios have been expressed.

First, as was discussed above, not all interpretations of DDE apply to end of life cases. This was the case with the interpretation by Warren Quinn. Second, some issues regarding the applicability of condition (4) arise. The reason for allowing the patient to die should be proportional to the suffering that is prevented. In the self-defence case discussed by Thomas Aquinas, for example, DDE allows one to kill in self defence. Here, condition (4) is satisfied because one life is saved (your own) and one is taken (the assailant's), creating a perfect balance. But how can the evil of causing death be weighed against the prevention of suffering, if non-accidentally causing the death of an innocent person is considered to be an absolute evil? The solution to this problem for DDE is, again, redescription. In order to make the Standard Vatican Case work, one has to redescribe death as a certain state of affairs. By viewing not death itself, but the span of time by which life is shortened, as what should be balanced against the reduction of suffering in an imminently dying person, a favourable equilibrium or an imbalance in the direction of the good might be achieved. If we assume that the difference between a 'natural' point of dying and the precipitated point of dying can be expressed as the description of some state of affairs (a counterfactual one), the proportionality can be assessed.

Thus the application of DDE to end of life decisions is not uncontroversial. Nevertheless, since many commentators do believe that the doctrine applies to these cases, this chapter will make abstraction from these difficulties and specifically discuss DDE's application to end of life cases and CDS. However, we do acknowledge that end of life cases might in some important respects be different from classical DDE cases. Our criticisms of the application of DDE to CDS need not therefore apply automatically to the application of DDE to other cases.

6.4 DDE and continuous deep sedation at the end of life

In the previous section, we have attempted to show how DDE is used as a justificatory principle in what we have called the Standard Vatican Case. When it comes to CDS, some commentators believe that the Standard Vatican Case is sufficient to justify this

practice, while others have modified the Standard Vatican Case to make it apply to CDS. In this section, we shall investigate whether any of these formulations can adequately justify CDS.

Applying the Standard Vatican Case

The first application of DDE to CDS that we will discuss comes from Joseph Boyle, who considers the Standard Vatican Case to be sufficient to justify CDS (see also Cavanaugh 2006). According to Boyle:

> The use of terminal sedation to control the intense discomfort of dying patients appears to be an established procedure within palliative care. But sometimes the amount of sedative needed to control suffering has the effect of shortening the patient's life (...) Invoking double effect addresses these worries [that terminal sedation might be a form of euthanasia]: the intent of the physician prescribing the life-shortening analgesics is to control the suffering, not to shorten life. (Boyle 2004, 51)

In order to illustrate the application of DDE to CDS more clearly, we can represent it schematically, after having introduced the following conventions. They are compatible, as far as we can see, with Boyle's interpretation of DDE, and start from the current standard account of intentions (following Anscombe (1958) and Bennett (1995)). According to this account, as mentioned earlier, one's intentions in acting are defined by which of one's beliefs explain one's acting that way. When acting, people have beliefs about what states of affairs they are bringing about and some of these beliefs explain why we do what we do: they are the reasons why we act. These beliefs are the *intentions* behind the act.

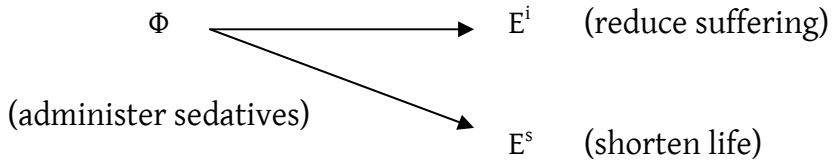
So:

> let Φ stand for a proposed act (e.g. administering sedatives);
>
> let E stand for a state of affairs that is an effect of doing Φ (e.g. reducing the patient's suffering);
>
> let i and s be indexes on E, denoting respectively 'intentional' and 'non-intentional' (side-effect);

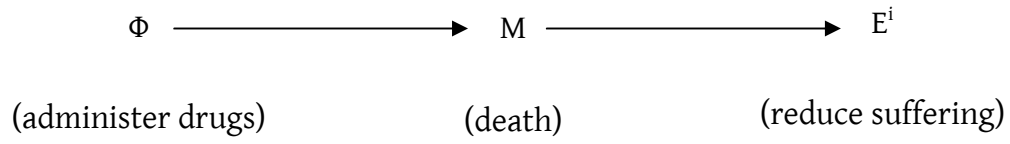
let M stand for an E that is intended as a 'means' (it is thus by definition an E^i); and

let A → B stand for 'A contributes to B' (with 'contributes' signifying either causal relations, or relations that are made true under some description of what is happening, or some other kind of contribution,[8] with A and B ranging over M, E, and Φ.

Boyle's statement above may then be represented as:



This is simply the Standard Vatican Case. Its counterpart may be called the Euthanasia Case:



According to this view, from the perspective of DDE there is no relevant difference between sedation and the alleviation of pain and symptoms with a possible life-shortening effect.

However, this application of DDE to CDS gives rise to some problems. First, some commentators do not agree that, in CDS, life-shortening is a side-effect. This is obviously a discussion about 'closeness'[9], where the answer to the question whether DDE

[8] For example, by allocating scarce medical resources to one group, another group may not get what it needs. Yet giving the resources to one group is not the *cause* of the other not getting what it needs. Similarly, omissions are not necessarily the *causes* of what happens, although they may *condition* that chains of events continue working as they are.

[9] See our discussion of the redescription problem above.

can be applied to CDS depends on how close one perceives the connection to be between administering sedatives and shortening of life.

A second problem with the formulation suggested by Boyle is that it does not consider loss of consciousness as either a means or a side-effect of CDS, even though CDS is a practice that *necessarily* includes loss of consciousness. Furthermore, reducing consciousness is not only *by definition* part of CDS, it could also be argued that permanently reducing consciousness can be considered an absolute wrong. Some commentators reject the latter claim and point to the fact that we have no obligation to always maintain consciousness. Indeed, we frequently reduce our consciousness (or allow it to be reduced) intentionally (e.g. undergoing general anaesthesia for painful surgery) or as a side-effect (e.g. consuming alcohol). There is, however, a relevant difference between these cases of lowering consciousness and continuous deep sedation, in that CDS *permanently* takes away consciousness. Taking away consciousness completely and permanently can constitute either a *direct* harm or an *indirect* harm. Paraphrasing Quinn, a direct harm is one that comes to its victim from the agent's intentionally involving her in something, so that the aim of the agent is furthered precisely by that involvement. An indirect harm is one that comes about even though it is either not intended in this purposive way for the victim, or what is purposively intended does not contribute to the harm (Quinn 1993, 184-5). Frances Kamm argues that CDS it is a direct harm:

> In terminal sedation, we intend (not merely foresee), on an occasion, the cessation of rational agency, though this will not be conducive to future rational agency. We even intend to prevent future rational agency, all done as a means of stopping pain. (Kamm 1999, 602)

On this view, taking away consciousness is bad, since it takes away all rational agency as a means of stopping pain. Moreover, unlike taking alcohol and undergoing general anaesthesia, which do not undermine *future* rational agency, CDS *does*, since the patient will not regain consciousness.

One could also argue that taking away consciousness permanently until death represents an *indirect* harm since it deprives the patient of the possibility to perform certain essential duties or even of the possibility to experience future pleasures. On this view, bringing a patient intentionally into a state of unconsciousness does not necessarily constitute a harm in itself, but it does harm the patient in a non-intended way. The Vatican seems to hold this view, as can for example be seen in an opinion of the Sacred Congregation for the Doctrine of the Faith (1980), according to which:

> [P]ainkillers that cause unconsciousness need special consideration. For a person not only has to be able to satisfy his or her moral duties and family obligations; he or she also has to prepare himself or herself with full consciousness for meeting Christ. Thus Pius XII warns: "It is not right to deprive the dying person of consciousness without a serious reason." (Sacred Congregation for the Doctrine of the Faith 1980, Section III)

But what constitutes a 'serious reason'? In his original speech, quoted from in the Declaration on Euthanasia, Pius XII seems to suggest that a serious reason for decreasing consciousness could be when continued pain or suffering gives 'opportunity for new sins'. (Pope Pius XII 1957, 41, authors' translation from Spanish), although what this means is somewhat vague. The more recent Declaration on Euthanasia lists three conditions for the rightful use of painkillers, including when they 'suppress' consciousness.[10] The first condition, known as the principle of last resort, is that no other means exist to relieve the patient's suffering. The second condition is that the suppression of consciousness should not prevent the patient from carrying out other religious and/or moral duties. In order words, the indirect harm inflicted by continuous sedation should be diminished as much as possible. The final condition is that death should in no way be intended or sought and that the intention must be confined to effective pain relief.

Some commentators assume that the 'serious reason' for causing unconsciousness is circumscribed by these three conditions for the rightful use of 'decreased' consciousness.[11] However, the passage that calls for a serious reason is clearly limited to 'painkillers that cause unconsciousness', i.e. to what we call continuous deep sedation.[12]

Accordingly, the text does not offer a full justification for permanently taking away consciousness. Again, undergoing general anaesthesia and consuming alcohol do not permanently impede one's capacity to fulfill certain (religious or other) duties, but taking away consciousness completely until death *does*. This seems to be precisely why

[10] The encyclical letter *Evangelium Vitae*, rephrasing the passage from the Declaration on Euthanasia, uses the expression '*decreased* consciousness'. (John Paul II 1995, 65, our italics)

[11] M. Davis, for example, summarises the two passages as follows: 'The [Sacred Congregation for the Doctrine of the Faith] reiterated Pope Pius XII's teaching on the use of terminal sedation. Painkillers that may cause unconsciousness may be used if no other treatment can relieve pain, and if the person has been given the opportunity to make his/her spiritual duties. The CDF emphasized that the intention in using these painkillers was to relieve pain and not to cause death' (Davis 2008, 1).

[12] The encyclical letter *Evangelium Vitae* reproduces the duality between 'mild' and 'deep' sedation. In the latter case, it uses the expression '*deprive* the dying person of consciousness' (John Paul II 1995, 65, our italics).

Pius XII, in his speech, made a strong distinction between, on the one hand, sedation that leaves the patient with some moments of competence and clarity (maintaining the possibility to fulfill religious duties), and, on the other hand, sedation that deprives the patient of all mental capacities and thus of all ability to do what should be done (e.g. to reconcile herself to God).

The latter kind of sedation, which is the topic of this chapter, was therefore clearly condemned by Pius XII when he said: 'Anaesthesia used at the approach of death, with the only goal of avoiding a conscious end of life for the patient, will not be a significant victory of modern therapeutics, but rather a truly deplorable practice ' (Pope Pius XII 1957, 42, authors' translation from Spanish). Apparently, the Sacred Congregation for the Doctrine of the Faith does believe that a proportionally sufficiently serious reason for permanently taking away consciousness might sometimes exist (but it does not clearly identify that reason).

Our main point however is that, whatever that reason may be, it is difficult to see how DDE could be applied to it in a plausible way. If one would accept that taking away (momentary) consciousness as a means (and thus intending it), is not a wrong in itself, it would still be necessary to show how it is possible to perform CDS without *also* intending to take away consciousness permanently (the so-called indirect harm). Consider the case of someone who would claim: 'Well, I intended to perform CDS, but only by taking away the patient's consciousness, albeit not permanently'. That amounts to a performative paradox.

The Non-Standard Vatican Case

Some commentators, for example Jansen and Sulmasy, have included 'permanent loss of consciousness' in their application of DDE to CDS:

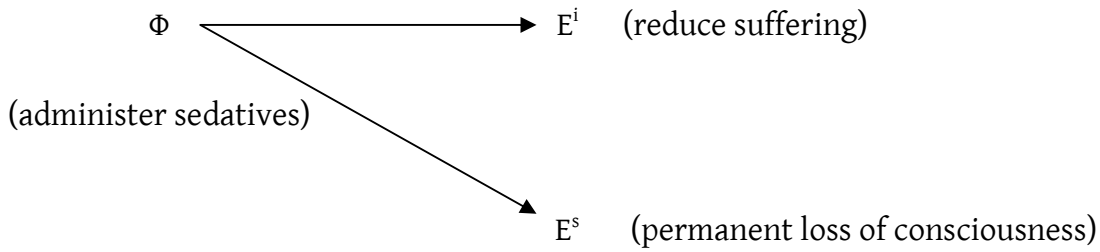
> The rule of double effect, when applied to the issue of terminal sedation, maintains that it is not immoral to render a patient unconscious as a side effect of treating specific symptoms if 1) one does not aim at unconsciousness directly, 2) unconsciousness is not the means by which one intends to relieve symptoms, and 3) one has a "proportionate reason" for taking such action. (Jansen & Sulmasy 2002, 847)

To make their view clearer, Jansen and Sulmasy introduce two contrasting cases. First, Joe's Case: Joe is terminally ill from cancer and his suffering is worsening. Because no other therapies help, his physician prescribes increasing doses of benzodiazepines until

the pain caused by the cancer is controlled. The dose required to achieve this control precipitates a coma. Joe dies two days later.[13]

This case is contrasted with Janet's Case: The facts are as in Joe's Case, but Janet's suffering is blocked by sedating her deeply.[14]

Thus, in Joe's Case, Jansen and Sulmasy start from the structure of the Standard Vatican Case, but modify it to include the permanent loss of consciousness as the relevant side-effect rather than the hastening of death. Put schematically:



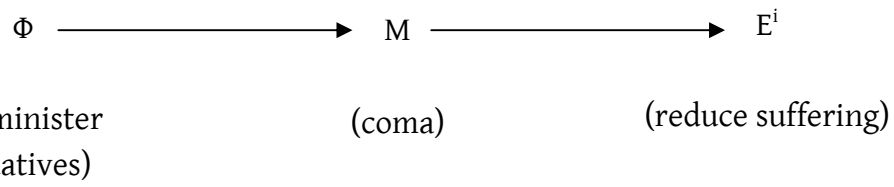
As mentioned above, some commentators note that loss of consciousness has the *additional* side-effect of preventing future experiences. For the sake of completeness, one could therefore include this as an additional effect to the permanent loss of consciousness. However, as this is not central to the application of DDE and would only complicate the scheme (as it would be a side-effect of a side-effect), we shall ignore this here.

This scheme can then be called the *Non-Standard Vatican* Case. It can be contrasted with Janet's Case, which Jansen and Sulmasy consider to be unjustified and to be more like the Euthanasia Case, where an undesirable means is used to produce a good effect. One could call Janet's Case the *Terminal Sedation Case* and schematically this would be[15]*:*

[13] This is a simplified case description. In fact, Jansen and Sulmasy also add the requirement of patient consent to their description, a condition that is altogether irrelevant to the validity of DDE.

[14] Again, Jansen and Sulmasy's case is different, as they let Jane ask to put her in a coma. Again, they confuse an application of DDE from the point of view of what a *physician* is allowed to do with the application of DDE to a *patient's* request to have consciousness taken away.

[15] Note that the Sacred Congregation for the Doctrine of the Faith believes that such a scheme can be justified, as shown above.



The Non-Standard Vatican Case seems to be a more accurate application of DDE to CDS than the Standard Vatican Case, since it explicitly includes permanent loss of consciousness as an unintended side-effect. In the Non-Standard Vatican Case, 'preserving consciousness' properly takes the place that 'preserving life' has in the Standard Vatican Case: consciousness is, like life, a fundamental good that should not be intentionally and permanently diminished or taken away for the sake of preventing or diminishing suffering. That consciousness is a positive good is often missed in discussions about the ethical acceptability of CDS: taking consciousness away, or diminishing it, is often implicitly seen as a neutral thing compared to the evil of shortening life. In fact, the claim that sedation does not intentionally shorten life is sometimes mentioned as its main virtue compared to *both* the Standard Vatican Case and the Euthanasia Case (Cavanaugh 2006).[16] Yet, consciousness, as the condition of any kind of *meaningful* life, is obviously a positive value. Heyse-Moore, for instance, points out that some patients, even in pain, seem to value it: 'We try to avoid sedating patients where possible. Patients don't usually like it, nor do their relatives. Preservation of consciousness is rightly seen as an important priority' (Heyse-Moore 2003, 469).

Nevertheless, some questions can be raised concerning the Non-Standard Vatican Case. First, although this application of DDE introduces preserving consciousness as a positive value in the debate, it does so *by leaving out possible life-shortening*. However, since CDS is often accompanied by a withdrawal of artificial hydration and nutrition, the possibility of life shortening cannot be excluded, and (if present) should be considered relevant for the application of DDE.

Second, and more importantly, DDE, in this version, does not serve as a justification for CDS, but rather as an answer to the question as to how to protect the value of consciousness when the pharmacologically induced and permanent diminishment of consciousness appears to be the only way (besides death) of reducing pain. According to

[16] According to Cavanaugh, the advantage of CDS is that in doing CDS, the doctor does not intend the life-shortening, unlike with euthanasia where the doctor intends the patient's death. Thus Cavanaugh ignores the role of 'permanent loss of consciousness' and the question as to whether one may use a coma as an intended means for pain or symptom relief.

this application of DDE, the *deliberate* use of sedatives to cloud consciousness constitutes a direct harm (as in Janet's Case) and is the equivalent of euthanasia. This is problematic for two reasons.

First, most of the definitions of CDS (or of 'palliative' or 'terminal' sedation) include the intentional lowering of consciousness. Gevers (2004), for example, uses the term 'terminal sedation' and defines it as: 'the administration of sedative drugs with the aim to reduce the consciousness of a terminal patient in order to relieve distress' (Gevers 2004, 360). However, when CDS is defined in this way, it describes a practice that is unjustified and impermissible according to the Non-Standard Vatican application of DDE.

Second, since CDS includes the administration of sedatives (i.e. consciousness lowering drugs), the question arises as to how a physician could administer these drugs while at the same time *not* intending to take away consciousness as a means to reduce suffering. Of course, different types of drugs are administered to patients at the end of life, and for some of these drugs, their administration need not necessarily be accompanied by an intention to lower consciousness. Certain analgesics and anxiolytics, for example, are administered with the aim of relieving pain and anxiety respectively, but have a sedative effect. In these cases, the reduction of consciousness could be claimed to be a side-effect.[17] However, the drugs most commonly used and recommended for sedation at the end of life, such as midazolam, levomepromazine, and propofol, have the lowering of consciousness as their primary function. In small dosages, the reduction is minimal (but still present), while in high dosages these drugs induce a deep coma. It is clear that the effect of these drugs is a reduction of consciousness, and that, when administering them, one cannot claim reduction or loss of consciousness to be a side effect. This is true even if one is aiming at the lowest possible reduction of consciousness.

One could attempt a redescription and construe the case so that loss of consciousness or coma is interpreted as a side-effect of the cutting off of neuro-physiological processes. ('I only had the intention to interrupt normal neurological processes, not to induce a coma!'). CDS would then fall under the Non-Standard Vatican Case and thus be justified according to DDE. The problem with this 'DDE-saving' reply is that consciousness is - depending on one's preferred theory of consciousness – either identical to brain processes or supervenient on them (i.e. determined by brain processes). Both

[17] Although these drugs can in fact also be used with the explicit aim of reducing consciousness.

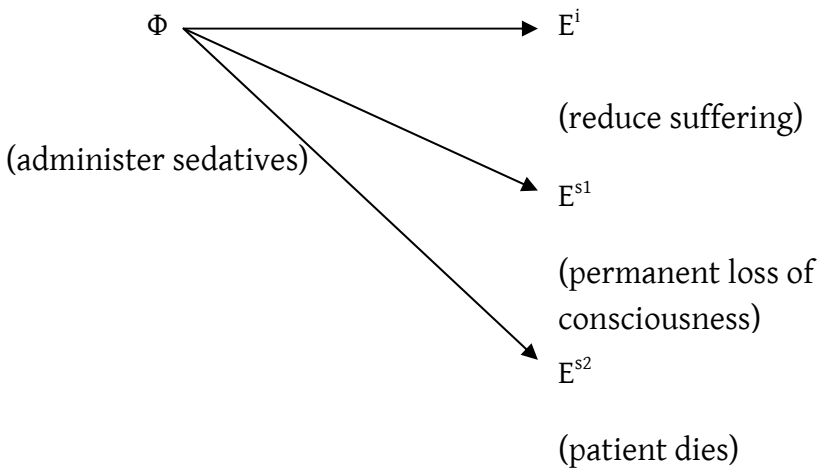
alternatives imply that the closeness between the physical processes and the experiential processes is infinite (their distance is zero). It is inconceivable (unless one adopts a dualist theory of the mind-body relationship) that conscious experience could survive the undercutting of its physical basis.

One might, however, still question whether using a *coma* as a means of relieving suffering is not in some relevant ways different from using *death* as a means to relieve suffering. For commentators such as Jonathan Glover it is clear: what is of value is not the 'biological life', but the consciousness that comes with it, and thus a 'life of permanent coma [is] in no way preferable to death' (Glover 1977, 45). This would imply that no ethically relevant difference exists between killing someone and permanently taking away her consciousness. Other commentators, however, see permanent coma as different from death for two reasons. First, they value life as such and claim that a patient in a coma can still be said to be alive (although permanently unconscious) and be allowed to die a natural death. Second, they note that CDS is – theoretically speaking – reversible. On these grounds, these commentators could claim that it is not incoherent to say that one may sometimes use permanent unconsciousness as a means to relieve suffering but never death.

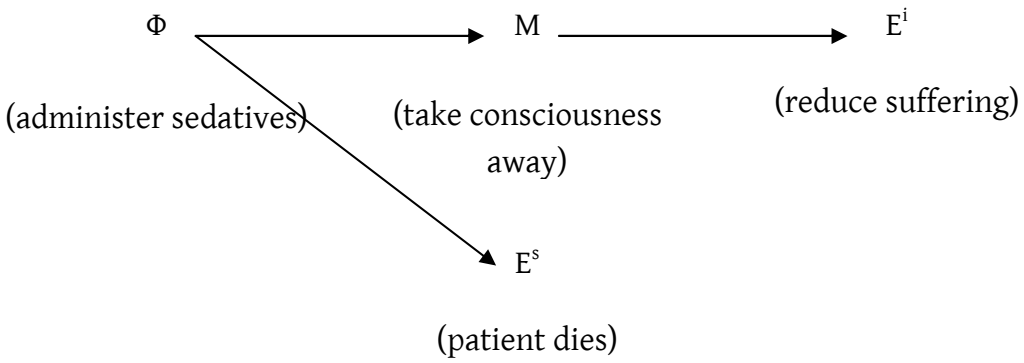
To this we would answer that, even if it is true that putting someone in a permanent coma is a lesser evil than killing that person, this does not make it a good. As we have argued earlier, there are good reasons to consider the permanent removal of consciousness as a wrong. Since we are dealing with *continuous* deep sedation, it is clear that the intention with which it is performed is to sedate the patient permanently until her death. Therefore, we would submit that inducing a coma for pain relief cannot become 'DDE-allowed' by claiming that inducing a permanent coma is a lesser evil than killing.

The Non-Standard Vatican Case and life-shortening

As noted in the previous section, the Non-Standard Vatican Case does not include the possible life-shortening of CDS. If we include the possible life-shortening, we would obtain the following scheme:



Or something like the following:



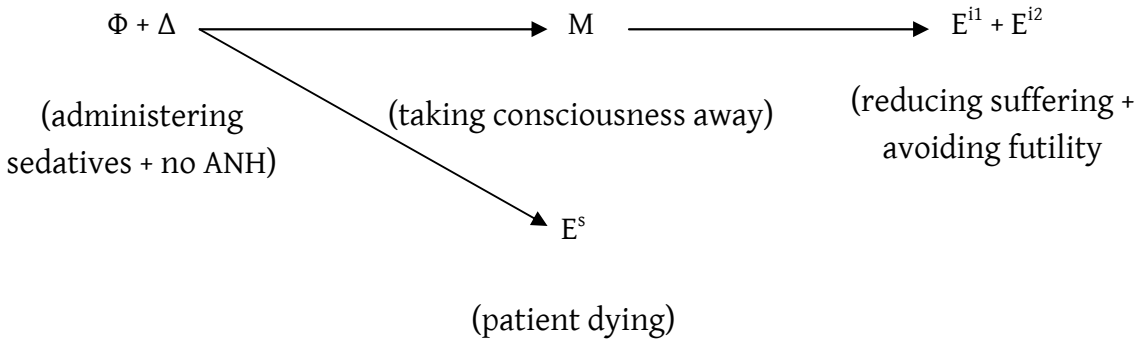
Both schemes have the advantage of including both the permanent loss of consciousness and the shortening of life as relevant means or side-effects, but both involve problems. In the first scheme, two bad-side effects (shortening of life and permanent loss of consciousness) have to be balanced against the good intended effect of reducing suffering. This might create a problem with the proportionality condition (although one might also argue that, since death is itself (permanent) unconsciousness, adding unconsciousness to unconsciousness makes no difference).

The problem with the second scheme is that, although death is considered here to be an unintended side-effect, it still remains the case that taking away consciousness is deliberately intended in order to reduce suffering. Thus, as in the Non-Standard Vatican Case, only those types of sedation where permanent loss of consciousness is a side-effect will be permitted and, as noted earlier, such a claim is unconvincing in cases of CDS.

It might, however, be possible to apply the 'proportionalist' version of DDE (discussed above) here, since this version allows an agent to use an evil as a means, provided that the good effect represents a good reason for doing so. In this case it could be claimed that – in some last resort cases – preventing suffering is a proportionate reason for using permanent loss of consciousness as a way of relieving that suffering. This interpretation of DDE, however, is controversial and can be said to have more in common with moral theories that allow a lesser evil to be committed to stop or prevent a greater evil, than it has with classical DDE.

Combining CDS with the withdrawal of artificial nutrition and hydration

The practice of CDS is often combined with the withholding or withdrawing of artificial nutrition and hydration (ANH). In Belgium, for example, the decision to use CDS has been reported to be combined with a decision to withhold or withdraw food and fluids in 57% of all sedation cases (Chambaere et al. 2010). It is therefore interesting to investigate whether and how DDE might apply to these cases, on the assumption that the life-shortening effect of withdrawing or withholding ANH may be real.[18] Schematically one could construe such cases as follows:



This application combines all the elements of CDS that are commonly thought to be relevant. Yet this application of DDE actually *combines two practices*, so in order to analyse this application one needs to look at the individual decisions.

[18] For example, Gillian Craig, a specialist in geriatrics, has noted that: 'If death is imminent few people would feel it essential to put up a drip but ethical problems arise if sedation is continued for more than one or two days, without hydration, as the patient will become dehydrated. Dehydration can result in circulatory collapse, renal failure, anuria and death'. (Craig 1994, 140). See also the discussion of this topic in chapters 1 and 3 of this dissertation.

Does DDE apply to the withholding of ANH? It is commonly claimed that DDE does in fact justify this, but only if, additionally, a distinction is maintained between *ordinary/proportionate* and *extraordinary/disproportionate* means.[19] In withholding *extraordinary/disproportionate* means (such as a ventilator), the patient is spared excessive pain from a treatment that offers no reasonable hope of benefit, even if withholding the treatment may shorten the patient's life. In these cases, all the conditions for classical DDE are fulfilled. However, when *ordinary/proportionate* means are withheld, DDE's proportionality condition is not met. Marquis, for example, argues that: 'A decision *not* to use *ordinary* means of sustaining life (...) is not justified by a *proportionate* reason to bring about the bad consequence. Hence, a physician who

[19] As explained by Donald Henke in an interesting overview of the history of the development, within the Catholic tradition, of the distinction between 'ordinary' and 'extraordinary' means (Henke 2007, 66-7), confusion arose from the way in which the health-care community used those terms, in contrast to their traditional theological meaning. Quoting Bryan Jennett (Jennett 2002, 105), Henke notes that, initially, 'ordinary was taken to mean generally available and widely used, whilst extraordinary would include advanced technological methods that were scarce and expensive'. With its Declaration on Euthanasia (1980), according to Henke, the Sacred Congregation for the Doctrine of the Faith attempted 'to clarify the distinction between what the medical community understood as the definitional characteristics of the terms ordinary and extraordinary ... and the theological understanding, which was significantly more nuanced than simple ease or difficulty in application ... The declaration proposed that the terms used by moral theologians and medical personnel should shift away from the ordinary-extraordinary distinction ... to a different set of terms that would be more specific'. (Henke 2007, 67) Indeed, in the Declaration on Euthanasia, the question is raised as to whether it is necessary in all circumstances to have recourse to all possible remedies. According to the Sacred Congregation for the Doctrine of the Faith: 'In the past, moralists replied that one is never obliged to use "extraordinary" means. This reply, which as a principle still holds good, is perhaps less clear today, by reason of the imprecision of the term and the rapid progress made in the treatment of sickness. Thus some people prefer to speak of "proportionate" and "disproportionate" means. In any case, it will be possible to make a correct judgment as to the means by studying the type of treatment to be used, its degree of complexity or risk, its cost and the possibilities of using it, and comparing these elements with the result that can be expected, taking into account the state of the sick person and his or her physical and moral resources'. (Sacred Congregation for the Doctrine of the Faith 1980, Section IV). Thus, as Henke rightly concludes, the key message from the Declaration in this regard is that whether a means is proportionate or disproportionate, cannot be decided by merely considering the means in themselves. Rather, contextual factors (including patient-specific factors) must also be taken into account.
In recent Vatican documents, the terms 'ordinary' and 'proportionate' appear to be used together. See for example the Sacred Congregation for the Doctrine of the Faith's *Responses to certain questions of the United States Conference of Catholic Bishops concerning artificial nutrition and hydration* (2007), approved by Pope Benedict XVI: 'The administration of food and water even by artificial means is, in principle, *an ordinary and proportionate means* of preserving life. It is therefore obligatory to the extent to which, and for as long as, it is shown to accomplish its proper finality, which is the hydration and nourishment of the patient. In this way suffering and death by starvation and dehydration are prevented'. (Sacred Congregation for the Doctrine of the Faith 2007, response to the first question; our italics)

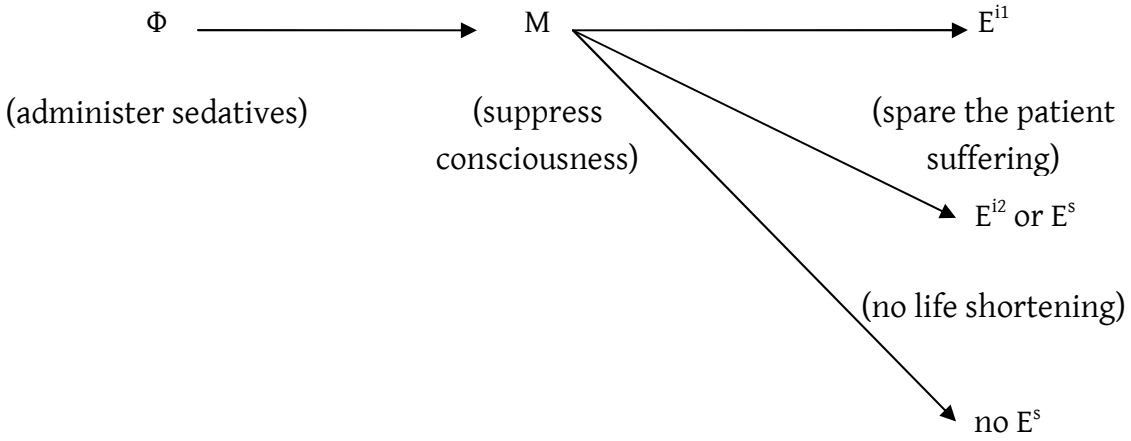
deliberately refrains from *ordinary* means of sustaining life *must be intending* the death of her patient' (Marquis 1991, 521).

The classical example of such ordinary/proportionate means is ANH. Thus DDE may justify certain non-treatment decisions, but *not* the withholding of food and fluids. Especially not in permanently unconscious patients, since these patients – being unconscious – can suffer no harm from the treatments they are receiving and so withdrawing food and fluids cannot be proportional to the suffering that is spared. The application of DDE to CDS combined with withdrawal or withholding of ANH therefore is problematic.[20]

Furthermore, even if one believes that withdrawing or withholding ANH is permitted by DDE, the use of sedatives to intentionally lower consciousness is not permitted by DDE, as we argued earlier. Accordingly, when combining these practices, one is at best adding a right to a wrong, thereby making a wrong.

The Non-Construable Case

Another possible case exists which we will call the Non-Construable Case. This is the most frequently encountered version in clinical and ethical discussions of CDS. Put schematically:



[20] According to proponents of the proportionalist interpretation of DDE, what constitutes *disproportionate* means depends on the particular circumstances and values at stake. In this interpretation, withdrawing ANH can sometimes be considered *proportionate* (e.g. if hydration and nutrition have side-effects that threaten a patient's dignity), making DDE potentially applicable. The proportionalist interpretation, however, is not the interpretation of DDE we are concerned with in this chapter.

In this case, consciousness is taken away in order to spare the patient suffering. There is no negative side-effect, but a second (either intended or unintended) positive effect, namely: not shortening life.

This case is not positively construable by means of DDE: Mangan's conditions (2) and (3) do not obtain because there is no bad effect. There are only two positive effects. One could, as noted earlier, claim that there is a negative side-effect since suppressing consciousness prevents further opportunities for positive acts or experiences. This point, however, is very rarely made in the literature on CDS and DDE. Moreover, this would still not make this case a case of DDE reasoning, since the line linking Φ to M and M to E^{i1} either simply represents a prohibition — if one believes that suppressing consciousness is not allowed in order to bring suffering under control — or describes intending a lesser evil in order to avoid having to intend a greater one.

We would submit that the morality that is at work in clinical practice regarding CDS is actually *not* DDE (in spite of all the lip service paid to this doctrine), but rather the morality of choosing the (seemingly) lesser evil over the greater one, i.e. consequentialism. This means that *directly intending* 'evils' (whether coma or death) should be allowed if one wants one's medical ethic to correspond to ongoing clinical practice. But whatever one may think about this, DDE does not apply to the kind of scheme mentioned above.

6.5 Concluding remarks

Although the Doctrine of Double Effect is a very frequently invoked justification for CDS, its application to this end of life practice turns out to be problematic. Classical DDE does *not* allow an intentional and permanent reduction of consciousness in order to diminish a patient's suffering. Only the construction under which the permanent loss of consciousness is a *side-effect* of administering sedatives rather than its end, is a candidate for a green light from classical DDE. In cases of CDS, such a claim is unconvincing.

We have also attempted to show that the most frequently encountered case in clinical ethical discussions is in fact not construable under DDE reasoning. The reason is that there is often claimed to be no bad side-effect for CDS, since the practice does not shorten life. So what happens in these justifications of CDS only *looks* like applying DDE. But what justifies CDS in this case is most clearly *not* DDE, but a different type of

reasoning that weighs the evil of taking away consciousness against the good of reducing suffering. This is an ethical justification which Magnusson has called 'the devil's choice', in which an agent finds herself in a situation where every choice available to her involves an evil, and she chooses the lesser one (Magnusson 2006).

This ethic seems to be the reason why the existing guidelines concerning CDS recommend the use of this practice only as a 'last resort'. The last resort case is of course the paradigm case where there is no good choice for the physician to make. In these cases, taking away consciousness is the only available way to reduce otherwise terrible suffering.

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Chapter 7
The clinical and ethical importance of measuring consciousness: the case of sedation at the end of life

Submitted for publication as journal article:

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7.1 Introduction

Continuous sedation at the end-of-life – the practice whereby a physician uses sedatives to reduce or take away a patient's consciousness at the end of life – is an end-of-life practice that has attracted much attention. Available research indicates that the practice is frequently used in, for example, Belgium (Chambaere et al. 2010), The Netherlands (Rietjens et al. 2008; Onwuteaka-Philipsen et al. 2012), and the UK (Seale 2010). The practice also raises many ethical concerns due, among other things, to its alleged similarity to euthanasia and to the seriousness of permanently taking away a patient's consciousness (van Delden 2007).

In response to the attention that is given to sedation and the concerns that are raised, guidelines are being drafted on the correct performance of the practice and its place within the broader context of end-of-life care. Examples of such guidelines are a framework drafted by the European Association of Palliative Care (EAPC) (Cherny & Radbruch 2009), a section in the Code of Medical Ethics of the American Medical Association (Levine 2008), a guideline drafted by the Norwegian Medical Association (Førde et al. 2008) and a Belgian (Federatie Palliatieve Zorg Vlaanderen 2010) and Dutch guideline (KNMG 2009). Only the Dutch guideline has legal ramifications, but these guidelines nevertheless indicate how, in different countries, medical professionals are recommended to use continuous sedation.

7.2 The requirement of proportionality in sedation guidelines and clinical practice

As noted above, various guidelines exist for continuous sedation at the end of life, and these guidelines differ in important respects. Nevertheless, an international consensus seems to exist about the importance of using sedation *proportionally to the severity of the symptoms* the patient is suffering from. For symptoms that cause less suffering, moderate sedation may suffice, while in cases of very severe suffering total unconsciousness may be necessary. The EAPC framework, for example, recommends that:

> In general, the level of sedation should be the lowest necessary to provide adequate relief of suffering. (Cherny & Radbruch 2009, 586)

The Dutch guideline contains a similar recommendation:

> It is crucial that [sedation] should be applied proportionately and adequately, in response to the appropriate medical indications (...). It is the degree of symptom control rather than the degree to which consciousness must be reduced that determines the dose, combinations, and duration of the drugs administered. (KNMG 2009, 18-19)

The idea is that a patient should only be made totally unconscious when this is required in view of her symptoms. In order to achieve proportionality, guidelines such as, for example, the Dutch National Guideline and the EAPC framework recommend a specific medication regime including which sedative drugs to use and in what dosages. However, even though these guidelines were meant to be drafted on empirical grounds, there is no strong evidence base specifically supporting the recommended dosages.

Qualitative research by Swart and colleagues suggests that proportionality also plays an important role in clinical decision-making:

> Although most interviewed physicians did not use the term "proportionality," their statements suggest that proportionality is a major factor in their decision-making process. (Swart et al. 2012, E363)

Interestingly, different approaches to achieving proportionality were observed among medical practitioners. Some physicians stressed the importance of starting with light sedation and increasing the dosage when necessary to relieve symptoms, while other physicians stressed the importance of starting with deep sedation, to guarantee that the patient is free from suffering.

Despite these differences in practice, all physicians were guided by the same objective, an objective that is also stressed by all existing guidelines: to assure that a patient is not sedated too lightly (the patient's suffering must be eliminated), nor sedated too heavily (as indicated by the symptoms). If this is indeed the central objective of continuous sedation, it would seem to be very important to adequately measure how deeply the patient is sedated, thereby allowing sedation to be increased where it is too light, and decreased where it is too heavy. The need for adequate measurement is increased by the fact that reducing or taking away consciousness also reduces communication skills, making it hard or even impossible for sedated patients to communicate their suffering

should they experience any. This makes obtaining the correct level of sedation even more important, since bringing patients into a situation in which they still experience suffering but are unable to communicate about it seems completely undesirable. Therefore, some commentators recommend that the initial dose of continuous sedation should be low enough to preserve some ability to communicate (permanently or periodically) and thereby allow reassessment of the situation (de Graeff & Dean 2007).

7.3 Evaluating proportionality: degree of suffering versus depth of sedation

In this article we will discuss ways to assess the proportionality of sedation by looking at the depth of sedation. One might also evaluate the proportionality condition by looking directly at a patient's suffering, since reduction of suffering is said to be the main goal of continuous sedation. Although being conscious is a necessary condition to experience suffering, it is not a sufficient one. Hence one might argue that demonstrating some degree of consciousness in a sedated patient does not necessarily imply a problematic level of suffering in that patient, and therefore does not necessarily indicate a badly proportioned sedation.

Nevertheless, in our view focusing on consciousness is the recommended approach for two reasons. First, as noted earlier, continuous sedation makes it very difficult or even impossible for more deeply sedated patients to communicate, and most assessment tools require cooperation from the patient. Using suffering rather than consciousness as the criterion for assessing proportionality thus makes assessment impossible in deeply sedated patients. Second, continuous sedation uses a reduction of consciousness as a means to relieve suffering but does nothing to take away the underlying causes of suffering (namely, symptoms which, according to all the guidelines, must be refractory and so *de facto* no longer responsive to treatment). Since the causes of suffering remain present, there is a considerable risk that for patients with refractory symptoms the presence of some consciousness *does* imply the presence of some degree of unpleasant experiences.

7.4 The ethical importance of consciousness

From an ethical point of view, the potential risk of (intentionally) hastening death is frequently seen as the most or even the only problematic aspect of continuous sedation. For example, in their influential literature review and recommendations for standards, de Graeff and Dean state that:

> The decision to offer sedation to relieve intolerable suffering during the last weeks of life presents no distinct ethical problem, provided that there is no intention to hasten death. (de Graeff & Dean 2007, 76)

However, we would argue that the fact that in continuous sedation, consciousness is permanently reduced or taken away, from an ethical perspective should also be seen as a potentially problematic aspect. In an interesting recent publication, Janssens, van Delden and Widdershoven argue that continuous sedation at the end of life is not just normal medical practice, as it is portrayed to be in the Dutch national guideline. Even if continuous sedation does not shorten life, it still permanently reduces consciousness and so they argue:

> Although justified in [some] case, a problematic aspect of palliative sedation remains undeniably the permanent reduction of consciousness until death. The very notion of 'last resort' [stressed in the Dutch national guideline] illustrates that only grave, proportionate reasons can justify such a far-reaching intervention. (Janssens et al. 2012, 667)

Indeed, from an ethical point of view, consciousness is valuable and should not be taken away lightly. Although most of us know that unconscious memories and thoughts play an important role in who we are as a person, when we reflect upon our own personhood, we are usually reflecting on what Damasio calls our 'autobiographical self (Damasio 2011), which does not constitute our body or our unconscious memories, but instead refers to the 'conscious me'. When we enter a state of permanent unconsciousness, we lose the ability to reflect upon ourselves and so with it disappears our autobiographical self. Thus, even though there might be disagreement on what exactly constitutes personhood, we would argue that taking away consciousness is not morally neutral and that a fundamental part of what it means to be a person diminishes or disappears when someone is continuously sedated until death. This has led some commentators to conclude that continuous sedation causes what might be called 'social death', implying that the often perceived gap between continuous sedation and euthanasia is a rather narrow one (Singer 2003; Janssens et al. 2012). Others, however,

argue that the personhood of continuously sedated patients is not diminished since they maintain the capacity for consciousness, for it is at least theoretically possible to bring sedated patients back to consciousness (Materstvedt 2012).

The moral significance of consciousness has been stressed by, for example, pope Pius XII, who is quoted in the Declaration on Euthanasia issued by the Sacred Congregation of the Doctrine of the Faith in 1980 as saying '[i]t is not right to deprive the dying person of consciousness without a serious reason' (Sacred Congregation for the Doctrine of the Faith 1980). The ethical importance of consciousness has also been argued for on non-religious grounds, for example by Frances Kamm who adopts a deontological perspective and argues that:

> In terminal sedation, we intend (not merely foresee), on an occasion, the cessation of rational agency, though this will not be conducive to future rational agency. We even intend to prevent future rational agency, all done as a means of stopping pain. (Kamm 1999, 602)

Finally, consciousness is also considered relevant from a utilitarian perspective, since being conscious is a pre-condition for having any experiences at all, both positive and negative. Peter Singer therefore observes that:

> Since the unconscious patient has no experiences at all, and does not recover consciousness before dying, the hedonistic utilitarian will judge terminal sedation as identical, from the point of view of the patient, to euthanasia at the moment when the patient becomes unconscious. (Singer 2003, 537)

Thus, in our view many guidelines are correct to emphasize that continuous sedation at the end of life should only be considered for serious reasons. As the Dutch guideline puts it, for example:

> [E]very physician must be aware that continuous sedation is a radical medical procedure, since it lowers the patient's level of consciousness until the moment of death. (KNMG 2009, 7)

Sometimes, of course, sedation will be necessary to relieve otherwise intractable suffering and in those cases, in our view, care must be taken to achieve the primary goal of continuous sedation, which is complete relief of suffering, while maximally protecting consciousness, as well as – of course – respecting the patient's wishes if known. Continuous *deep* sedation, where a patient is brought into a coma-like state, may

always be effective in relieving suffering, but when relief can be achieved with lighter sedation, the latter is morally preferable in our view.

7.5 Clinical characteristics of consciousness

As argued above, obtaining the correct level of consciousness is crucial in sedation. However, in practice, this proves to be very difficult for a number of reasons. First, consciousness is a complex phenomenon whose precise nature remains unclear. It is unclear exactly how sedative agents such as propofol and midazolam, and volatile agents such as isoflurane and desflurane, reduce consciousness (Mashour 2010). Various theories have been proposed that attempt to explain the precise workings of anaesthetics and sedatives (Alkire et al. 2008).

Second, in practice, accurately assessing the depth of a sedation is difficult enough for anaesthesiologists in cases where patients are temporarily sedated to undergo surgery (Shafer & Stanski 2008), and even more so for patients who are in their last weeks or days of life, who might be taking lots of different medications, and who are often suffering from multiple pathologies and/or organ failures, potentially influencing the workings of anaesthetic and sedative agents.

A third reason for the difficulty of achieving the correct level of sedation might be that in anaesthesia and sedation there is not one single goal, but rather three different goals. In a successful sedation, one obtains hypnosis (a state of deep sleep), amnesia (the patient does not remember anything that happened during sedation), and immobility (the patient is made immobile to a certain degree). Research has shown that due to the complexity of consciousness processes and interpersonal variability it is possible that in at least some cases, some of these goals are not obtained while the others are (Sandin et al. 2000; Mashour 2010). The possible scenarios are represented in Table 6.1.

Table 6.1 Possible scenario's

	Hypnosis	Amnesia	Immobility
1. Classical intra-operative awareness	No	No	Yes

2. Intra-operative awareness without recollection	No	Yes	Yes
3. Implicit memory formation	Yes	No	Yes

A classical example of a scenario where things go wrong is called 'intra-operative awareness'. Here patients are unable to move during surgery, but report being aware and remember the experience afterwards. This can range from full blown awareness to so called 'near-miss experiences', where patients have dreams that can be related to intra-operative events (Ghoneim et al. 2000; Leslie et al. 2007). Cases like these can potentially be very traumatic for patients and in certain cases, intra-operative awareness has led some patients to develop post-traumatic stress disorder (PTSD) (Lennmarken & Sydsjo 2010). These cases also pose difficulties for physicians because the patients *appear* to be adequately sedated, but are in fact aware. As yet, research to measure the presence and incidence of awareness during sedation has focused solely on patients who are sedated for the purpose of surgery, and to our knowledge almost no research has been conducted regarding levels of awareness in patients who receive continuous sedation until death. We will come back to this.

In a second possible scenario, patients are awake during surgery, but are immobile and have no recollection of being awake afterwards. The possibility of this scenario is shown, for example, by research from Enlund & Hassan (2002) who interviewed patients after surgery about their experiences while sedated. They reported 5 cases of patients who had been lightly sedated during surgery and even opened their eyes and moved, but had no recollection of this afterwards. This kind of awareness might also pose problems, for while patients might not be able to remember their suffering afterwards, they nevertheless might have had unpleasant experiences while being sedated. This raises the question as to whether remembrance is necessary for a certain experience to be considered suffering.

A final scenario is where patients are immobile and fully unaware, but nevertheless build up certain memories. This is sometimes called 'implicit memory formation'. A lot of research has been done concerning the formation of implicit memories while being sedated. For example, sedated patients would hear certain words read out continuously. Once awake they were asked to complete word stems (e.g. APP___), and patients showed a tendency to form words that were read out to them during sedation (Kerssens & Alkire 2010). Whether this is a problem is a topic of debate. Some believe that 'implicit learning' is present at every level of anaesthesia or sedation and can therefore not be

avoided. To our knowledge, no data are available that show implicit learning to be in any way associated with suffering.

The preceding discussion highlights the complexity of consciousness since patients who seem to be peaceful might in fact be both fully aware and experience suffering. This can, for example, also be seen in cases of hypoactive delirium where critically ill patients are suffering due to delirium but show little or no outward signs of being distressed (Spiller & Keen 2006). Research indicates that hypoactive delirium is the most common subtype of delirium (Fang et al. 2008), and that patients with hypoactive delirium experience the same amount of distress as patients with hyperactive delirium (Breitbart et al. 2002). These findings are clearly relevant for patients who are continuously sedated until death.

7.6 Measuring consciousness

The problem of potentially undetected awareness in sedated patients has generated a lot of research and debate in the international anaesthesia literature, particularly regarding tools for measuring the depth of anaesthesia (Shafer & Stanski 2008). Various tools that range from clinical assessment scales to EEG derivatives have been suggested.

As mentioned above, to our knowledge almost no research exists concerning the depth of sedation in patients who are continuously sedated until death. Yet such research is urgently needed since:

(1) The goal of continuous sedation at the end of life is to provide a peaceful and dignified end of life for patients, free from suffering. In the absence of research, it remains possible that at least for some *seemingly* sedated patients this goal is not reached.

(2) Patients who receive continuous sedation are potential risk cases for anaesthetic awareness due to the fact that these patients are in a very poor physical state, which might influence the workings of sedative agents.

Therefore, in this section we will review the most important tools for measuring the depth of sedation that are suggested in the general anaesthetic literature: basic clinical assessment, use of scales, EEG, and EEG derivatives. Our aim is to consider their relevance to the clinical practice of continuous sedation at the end of life.

Basic clinical assessment

Probably the most commonly used tool to assess proportionality and depth of sedation in cases of continuous sedation is basic clinical assessment. Here the physician administers sedatives to a patient and observes whether they put the patient in a comfortable sleep. If the patient shows signs of being awake (for example groaning while being washed or handled), dosages can be increased.

However, various studies have shown that this approach is problematic since it reduces 'consciousness' to 'responsiveness to certain stimuli' – thereby making the caregiver the tool of measurement – whereas recent research has shown that patients can be unresponsive and yet aware (Noreika et al. 2011). Moreover, the accuracy of clinical assessment is likely to be dependent on how often the physician comes into contact with sedated patients. This is relevant for continuous sedation since this practice is often performed by family physicians or clinical specialists, who have fewer experiences with sedated patients than anaesthesiologists and might therefore have a less accurate clinical assessment. Once initiated, further monitoring of the depth of sedation is done by the medical caregivers.

Thus, while basic clinical assessment might allow to distinguish sedated patients from fully awake patients, it lacks the subtlety to correctly assess proportionality in continuously sedated patients. As noted by Rinaldi et al.: 'Direct clinical observation allows a rough distinction between adequate, excessive and inadequate sedation, although with poor validity and reliability' (Rinaldi & De Gaudio 2006, 305)

Use of assessment scales

Using scales to measure the level of consciousness is a more objectified way of clinically assessing patients, and many scales have been proposed (Rinaldi & De Gaudio 2006). In these scales a rating is usually assigned on the basis of a patient's clinical characteristics and – more importantly – her responsiveness to external stimuli. A well known example is the 'Ramsey Sedation Scale (RSS)' (Ramsay et al. 1974) shown in Table 6.2.

Table 6.2 Ramsay Sedation Scale

Score	Response
1	Anxious or restless or both
2	Cooperative, orientated and tranquil
3	Responding to commands
4	Brisk response to stimulus
5	Sluggish response to stimulus
6	No response to stimulus

Another frequently used scale is the Observer's Assessment of Alertness/Sedation Scale (OAA/S) (Chernik et al. 1990) shown in Table 6.3. This scale could be useful for monitoring continuous sedation at the end of life, since it was validated with intravenous midazolam, the drug most commonly used for this practice.

Table 6.3 Observer's Assessment of Alertness/Sedation Scale (OAA/S)

Assessment categories				*Composite score level*
Responsiveness	**Speech**	**Facial expression**	**Eyes**	
Responds readily to name spoken in normal tone	Normal	Normal	Clear, no ptosis[1]	5 (Alert)
Lethargic response to name spoken in normal tone	Mild slowing or thickening	Mild relaxation	Glazed or mild ptosis (less than half the eye)	4

[1] Ptosis means the drooping or falling of the upper or lower eyelid.

Responds only after name is called loudly and/or repeatedly	Slurring or prominent slowing	Marked relaxation (slack jaw)	Glazed and marked ptosis (half the eye or more)	3
Responds only after mild prodding or shaking	Few recognizable words	-----	-----	2
Does not respond to mild prodding or shaking	-----	-----	-----	1 (Deep sleep)

For this scale, all the categories need to be checked, with the composite score 'corresponding to the lowest level at which any statement is checked' (Chernik et al. 1990, 245). As with the Ramsey scale, the physician using the OAA/S Scale must stimulate the sedated patient to assess the level of sedation.

A third important scale is the Richmond Agitation – Sedation Scale (see Table 6.4), developed by Sessler et al (Sessler et al. 2002). An advantage of this scale is that it was initially developed for monitoring depth of sedation for critically ill patients in an intensive care unit, who are more comparable to terminally ill patients receiving continuous sedation at the end of life than more or less healthy patients undergoing anaesthesia for surgery. The use of this scale to monitor depth of continuous sedation is also recommended by the European Association of Palliative Care's framework on palliative sedation (Cherny & Radbruch 2009).

Table 6.4 Richmond Agitation-Sedation Scale

Score	Term	Description
+4	Combative	Overtly combative or violent; immediate danger to staff
+3	Very agitated	Pulls on or removes tube(s) or catheter(s) or has aggressive behavior toward staff
+2	Agitated	Frequent nonpurposeful movement or patient-ventilator dyssynchrony

+1	Restless	Anxious or apprehensive but movements not aggressive or vigorous
0	Alert and calm	
-1	Drowsy	Not fully alert, but has sustained (more than 10 seconds) awakening, with eye contact, to voice
-2	Light sedation	Briefly (less than 10 seconds) awakens with eye contact to voice
-3	Moderate sedation	Any movement (but no eye contact) to voice
-4	Deep sedation	No response to voice, but any movement to physical stimulation
-5	Unarousable	No response to voice or physical stimulation

Using scales in clinical practice has several advantages. For example, it allows a physician to have her score for a certain patient checked by a colleague, and a physician can score a sedated patient at various times, allowing her to monitor the fluctuation in anaesthetic depth. Another advantage is that using these scales does not require great expertise. A final important advantage is that this method is 'low-tech' and inexpensive: using a sedation scale does not require monitoring patients with expensive machines.

However, although existing sedation scales are currently being used and recommended, few of these scales have been validated for palliative care patients or patients receiving continuous sedation at the end of life. We know of only one scale, the Consciousness Level Scale for Palliative Care, which was designed and validated (on a small scale) for use in palliative patients by relating the scale's sedation scores to the scores of other existing scales (Gonçalves et al. 2008). For patients under continuous sedation, we know of only one study in which four sedation scales were used to measure consciousness of patients receiving continuous sedation at the end of life (Arevalo et al. 2012). In this study the validity and reliability of four sedation scales were tested by comparing the scales with each other, on the basis of the hypothesis that if all these scales measure the same thing, namely depth of consciousness, their scores should be correlated. However, the researchers responsible for the study note that: 'content validity and internal consistency of the scales were not evaluated' (Arevalo et al. 2012, 707). In sum, even though some work has been done comparing existing scales to each other, no research appears to have been done to date which investigates the value of using sedation scales in continuously sedated patients by, for example, comparing sedation scale scores to

other – independent – sources of information regarding depth of sedation, such as an EEG monitor or EEG derivatives (see below).

Moreover, even if the scales discussed above would turn out to be as applicable to patients receiving continuous sedation at the end of life as they are to other patients, questions remain concerning both the effectiveness and the invasiveness of sedation scales. With regard to effectiveness, concerns are sometimes voiced since sedation scales fall victim to the same concerns as basic clinical assessment. What these scales measure is response to stimuli, but 'clinical unresponsiveness is not necessarily synonymous with unconsciousness' (Alkire et al. 2008, 877), thus it is possible that patients who do not respond to stimuli are nevertheless conscious and capable of suffering.

As regards invasiveness, it is indeed true that these scales do not require putting patients on machines and placing electrodes or other sensors on their bodies, but in an important sense they *are* invasive. As mentioned earlier, when using these scales, physicians need to stimulate the patient, for example by calling out her name, prodding, shaking or even providing painful stimuli (for example a trapezius squeeze). With regard to the OAA/S scale, Liu et al. note that:

> This technique of assessment requires that the patient be stimulated at frequent intervals (...), a practice that can be disturbing to both the patient and the [physician]. A further limitation of the OAA/S scale is that it requires the patients' cooperation and is subject to testing fatigue. Therefore, the availability of a reliable, noninvasive sedation monitor would be highly desirable (Liu et al. 1996, 64)

Finally, although clinical scales allow medical practitioners to track fluctuations in anaesthetic depth, they do this in a way that often lacks the subtlety to track small (but important) changes in depth of anaesthesia or sedation (Blumenfeld 2009).

For these reasons, using scales such as the Ramsey, OAA/S and Richmond Agitation-Sedation scales in palliative patients, for measuring the depth of a continuous sedation at the end of life, may be problematic since they can be invasive and might not be very effective.

EEG

The organ that is unquestionably responsible for the generation of consciousness and awareness is the brain. Different techniques have therefore been proposed to measure

the presence or absence of awareness by looking directly at brain activity. A first technique would be to analyze the electroencephalogram (EEG), which measures postsynaptic activity in the brain (i.e. the fluctuation in voltage as a result of the flow of ions within brain neurons).

Looking at raw EEG data has the advantage that it measures brain activity directly rather than measuring responsiveness. That said, the unprocessed EEG also has many disadvantages. It requires placing electrodes on a patient's scalp, which might be particularly problematic and invasive for dying patients. Also, and more importantly, a raw EEG produces a great amount of information that is not relevant for measuring awareness. Furthermore, different anaesthetic and sedative drugs have different effects on the EEG pattern. Correctly analyzing all this information therefore requires great expertise and cannot be done quickly.

EEG derivatives

Some techniques have been developed that process the EEG signal to generate a more readily usable value. These techniques attempt to find an EEG parameter that is reliable and drug-independent. Possible candidates include the changes of the EEG over time, the frequency of the EEG signal, its amplitude, or a combination of some of these parameters. These techniques were designed to reduce the incidence of intra-operative awareness in surgery, but might also be applicable to measure awareness in the context of continuous sedation at the end of life.

Examples of parameters that are calculated include spectral edge frequency (95% SEF), median power frequency (MPF) and Entropy. A technique whereby EEG parameters are combined is the Bispectral Analysis of the EEG (BIS), which is a subject of hot debate in the anaesthetic literature. We shall take a closer look at it, as it is particularly relevant in the context of the topic of this chapter.

Bispectral Analysis 'combines the frequency domain analysis of the EEG with the quantification of the degree of phase coupling between the waves included in the EEG' (Rinaldi & De Gaudio 2006, 312). The results have been correlated empirically to different clinical levels of sedation and different dosages of drugs, to create a scale ranging from 0 (isoelectricity) to 100 (awake state). The advantage of this technique is that it replaces complex EEG patterns with a single number, making it a highly practical and easily interpretable tool.

BIS monitoring might have more advantages than sedation scales in terms of both effectiveness and invasiveness. It might also be of particular interest for patients who are continuously sedated until death. When it comes to BIS's effectiveness in assessing anaesthetic depth, however, there is some debate. One of the problems is that the depth of sedation with certain sedatives and anaesthetics (e.g. ketamine, halothane, and nitrous oxide) has not been validated for BIS, making it questionable whether the current BIS scale is valid when these drugs are used (Park et al. 2006). However, none of these drugs are commonly used in continuous sedation at the end of life, for which midazolam is the drug most often recommended. Not only has BIS been validated for midazolam, but a study indicates that BIS is a good predictor of the depth of midazolam induced sedation (Liu et al. 1996). Another advantage of BIS monitoring is that it allows a constant monitoring of sedation rather than a measurement of depth at certain intervals of time (as, for example, with clinical assessment scales). Thus, it enables a quick response to subtle changes in patients' awareness.

As regards invasiveness, BIS monitoring does require placing an electrode patch on a patient's forehead,[2] but once applied the patient is left alone and does not need to be stimulated in any way. This is an advantage over clinical assessment and the use of scales, perhaps making BIS the 'reliable, noninvasive sedation monitor' (Liu et al. 1996, 64) the need for which this chapter aims to demonstrate.

Nevertheless, the debate over which is preferable, BIS monitoring or clinical scales, continues. Some research has been undertaken where a patient's BIS level is compared to her score on a sedation scale (usually the OAA/S or the RASS scale) to check for correlation. However, this research has produced very different results (Ibrahim et al. 2001; Chisholm et al. 2006; Weaver et al. 2007) and, importantly, has *never* been performed for patients receiving continuous sedation at the end of life. While some of the studies suggest that BIS monitoring and sedation scales do not always correspond very well – leading the authors to conclude that BIS has little applicability in clinical practice – others suggest that BIS *does* in fact correlate well with the Richmond Agitation – Sedation Scale (RASS) (Karamchandani et al. 2010). A disadvantage of BIS, according to some commentators (O'Connor 2001), is that it is expensive to use, and that, because awareness while being sedated is said to be rare, preventing a few cases of sedated awareness would involve a significant cost.[3]

[2] Normally this would be one patch per day.

[3] We have checked the prices for Belgium. A reusable BIS VISTA Monitor costs 3.557,11 EUR, and the individual sensors or patches cost 13,63 EUR/piece. To monitor a sedated patient would require a new patch every day,

7.7 Concluding remarks

In clinical guidelines as well as in the (medical) ethics literature, proportionality is claimed to be of key importance when administering continuous sedation at the end of life. To ensure that the criterion of proportionality is met, it seems crucial that the depth to which a patient is sedated is measured and/or monitored in some way. If a physician does not know to what extent a sedated patient is aware, how can she be said to be sedating proportionally?

Different tools for measuring anaesthetic depth are widely discussed in clinical literature, yet, highly surprisingly in our view, the use of these tools for terminally ill patients who need continuous sedation at the end of life is simply not being debated. Nor does any research appear to be conducted regarding the depth to which these patients are sedated. Currently, clinicians mostly rely on clinical assessment and sedation scales, even though little knowledge is available as to whether a physician's assessment always correctly corresponds to the estimated depth of sedation.

Moreover, we have argued that clinical assessment and sedation scales are not necessarily the most effective or even the least invasive procedures currently available. We would therefore urgently recommend more research, for example by measuring the level of awareness of patients who are continuously sedated until death by using EEG derivatives such as BIS, or by correlating the BIS value with the clinical assessment of a physician. We are aware of one research project with dying patients, namely a case series of 7 patients whose level of awareness was measured until death by using a BIS monitor (Chawla et al. 2009). All patients showed a spike of awareness in BIS activity, close to a level one would expect of a conscious person. The researchers offer no definitive explanation for this spike of awareness but speculate that it might be due to a reaction of the brain in response to a critical shortage of oxygen (hypoxia). This suggests that a larger study in which the level of awareness of sedated patients is measured by BIS (or another EEG derivative) may yield results which would not only be interesting from a scientific point of view but which, in view of the ethical importance of consciousness and thus of ensuring that sedation be proportionate, would also be highly welcome from an ethical perspective.

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but since the average length of a continuous sedation is short (a few days), we believe that BIS monitoring such patients cannot be said to involve significant costs.

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Part 3

The (perceived) practice of sedation

Chapter 8
Factors that facilitate or constrain the use of continuous sedation at the end of life by physicians and nurses in Belgium: results from a focus group study

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8.1 Introduction

It is becoming more and more common that in the care of terminally ill patients, decisions are taken that can potentially have an effect on the patient's time of death (Bilsen et al. 2009). One such end-of-life decision is continuous sedation at the end of life (CS) where a physician uses sedatives resulting in the reduction or taking away of a patient's consciousness until death.[1] Various types of continuous sedation exist; sedation can be light (patient can still be woken) or deep (patient is in a coma-like state), and can be induced suddenly (in response to an acute problem) or be the result of a gradual increase of sedative medication (in response to gradually worsening symptoms). Research in Belgium indicates a high (and rising) incidence for CS: in Belgium, the practice was used in 8.2% of all deaths in 2001, and this number rose to 14.5% of all deaths in 2007 (Bilsen et al. 2009). Accordingly, medical practitioners deal more and more frequently with patients who are continuously sedated until death, and the practice has, arguably, become part and parcel of palliative care.

Nevertheless, various differences seem to exist in the frequency with which and the reasons why medical practitioners use continuous sedation at the end of life. As regards frequency, for example, CS was used in 16.5% of all deaths in the UK in 2007-2008 (Seale 2009), whereas in The Netherlands it was used in 8.2% of all deaths in 2005 (Rietjens et al. 2008), and this number rose to 12.3% in 2010 (Onwuteaka-Philipsen et al. 2012). Concerning the reasons why CS should be initiated, existing guidelines leave some room for interpretation. One example of a difference in national practices is that in The Netherlands in 2001, in accordance with a Dutch guideline (KNMG 2009), the initiation of CS was requested or consented to by the patient in 59% of cases (Rietjens et al. 2004), while in Belgium in 2007, a request for or a consent to continuous sedation was obtained in only 30% of cases (Chambaere et al. 2010). This indicates that there might be many factors influencing whether, why and when medical practitioners decide on CS. However, little is known as to what those factors might be and how they influence the medical professionals. Our focus group research attempts to shed light on this issue and to answer the following question: 'What, according to physicians and nurses in Belgium, could make it more or less likely that continuous sedation will be used in a particular

[1] Among the other terms that are used to refer to this practice are 'terminal sedation' and 'palliative sedation'.

case?'. In other words, which factors could facilitate Belgian physicians and nurses in choosing to use continuous sedation, and which factors could constrain them in making such a choice?

8.2 Methods

We asked physicians and nurses about their experiences with and their attitudes towards the practice of continuous sedation at the end of life. The participants in our focus groups were also specifically questioned about situations in which they would consider their involvement with continuous sedation to be psychologically more or less difficult.

Participants

In April 2010, we conducted two focus groups with physicians (n=4 & n=4), and two focus groups with nurses (n=4 & n=9) The participants were selected with the inclusion criterion that they had to have been involved in at least one case of CS in their entire professional career. The participants came from a balanced mix of settings (home care, hospital oncology wards, and hospital palliative care units or palliative support teams).

For the recruitment of the participants, we sent out invitations to physicians and nurses from the home care setting, the hospital oncology setting and the palliative care setting, asking them to participate in our focus group study. Professional registries (of the Belgian National Disciplinary Board of Physicians and the Belgian Society for Medical Oncology) were used to contact many physicians at once. Subsequently, we also contacted particular physicians, whom we know or who have contributed to earlier research of our research group, by e-mail or telephone in order to obtain a balanced mix of settings.

Focus groups

Each focus group was moderated by two moderators with considerable experience in (qualitative) end-of-life care research and moderating focus groups. Also present were observers taking field notes. Before the focus group discussions started, anonymity of data was discussed and informed consent for the electronic recording of the

proceedings was obtained. All focus group discussions lasted about two hours and were guided by an aide-memoire (i.e. a document containing the key questions to be asked as well as potential sub-questions or prompts) covering several topics: (1) general thoughts on CS; (2) general experiences with the practice; (3) attitudes towards CS; and (4) circumstances in which the participants would consider their involvement in continuous sedation to be more or less problematic

Data analysis

All focus group discussions were recorded electronically and transcribed verbatim, removing all data that could possibly identify the participants. For analysing the transcribed data, constant comparative analysis was used. Two junior researchers reread the transcripts separately and developed a preliminary coding to identify the most important themes and ideas.

Subsequently, on the basis of this preliminary coding, a coding tree was made and discussed within the research team and served to cluster relevant concepts. There were only minor differences in interpretation between the members of the research team and, after discussion, consensus was always reached. Next, the coding tree was used to go back to the uncoded transcripts to check whether it covered all relevant ideas. Again, this was done separately by the junior researchers, and double-checked by two senior researchers. After some minor adjustments, the coding tree was finalised. The qualitative analysis software used for this research was NVivo9.

8.3 Results

This section provides an overview of the circumstances and factors that, according to the participants, could affect the likelihood that sedation would be used.

The patient's current state

The state that the patient is in at the time that CS is considered, was mentioned as being important by the focus group participants. A clear facilitator for deciding to use the practice is that the patient is suffering severely and has a short life-expectancy. A good

indicator for a short life-expectancy was said to be when the patient herself stops taking in food and fluids.

> **Nurse P:** You have to do it in the final phase [of life] and not with patients who are suffering from symptoms but are still eating and drinking. Patients who are still eating and drinking will perhaps live for one or two months.

> **Physician F:** Time must be short, you have to be close to the expected end of life and actually, practically speaking, it boils down to when someone no longer can or wants to drink, so when somebody is no longer taking in fluids. Then we can presume that somebody will die within about fourteen days. Then, for me, it is possible to sedate, to continuously sedate. Otherwise it's never possible, because then you are going to make different decisions.

However, when a patient's suffering was deemed to be existential[2] rather than physical, this could be perceived as a psychological barrier by the focus group participants.

> **Nurse D**: But existential suffering, I find one of the most difficult issues. When you see the patient's suffering and we want to solve it all and then it's easy when the patient is sleeping quietly.
> **Nurse CL:** But whether that's solved with sedation, I'm afraid not. I'm afraid not.
> **Moderator:** What do you mean by that?
> **Nurse CL:** Well, that patients go through their sedation with their suffering continuing. That it happens under a different form, of nightmares and images and such. But I'm afraid they are not relieved from it.

> **Physician A:** So psychological unbearableness, to mention only one example. So for me it's psychologically unbearable but she [the patient] is not vomiting, is not experiencing pain,... . In such cases I would actually find it difficult to start up sedation.

[2] By existential suffering, we mean a type of psychological suffering where a patient suffers from loss of meaning in her life.

Deliberation and communication

Presence or absence of good communication between all parties involved was mentioned as a factor that could greatly impact on the likelihood that CS would be performed.

Request from the patient

If a clear request from the patient had been made, the participants in the focus groups mentioned they would feel more comfortable in performing CS.

> **Physician M:** People can be conscious and really choose palliative sedation, and that is, I think, a comfortable situation. Also for the patient herself, because she plays a role in the decision and to some extent even determines the moment [sedation is initiated].

Nevertheless, the focus group participants mentioned that a patient request was not always possible, and this was perceived as a barrier, for example when people at the end of life have diminished cognitive capacities.

> **Physician M:** And then you get into a situation where it may no longer be possible to discuss everything. Or metastases in the brain that make people confused, or other causes that make them confused and that sometimes leave you no other option than to use palliative sedation. I find that a less comfortable situation for the physician. I prefer it to be discussed in a straightforward manner, both with the patient and others...

Another important reason why a request was not always possible, was that patients were not always aware of the existence of continuous sedation and the physician did not bring it to their attention for fear of inducing the patient, meaning that the physician did not want to unduly influence the patient to choose CS.

> **Nurse C:** Hardly any patients know of the possibilities of sedation.
> **Nurse N:** Indeed.
> **Nurse C:** I think few patients will ask the question: 'Now I want to be sedated'. They don't know about the practice.
> **Nurse N:** No. They won't ask that question. But our physician insists on that question, not literally a request for sedation, but a patient indicating ' I can't go on', 'I want to sleep' mainly or 'I've had enough', because he is scared that, otherwise, we are going to induce things.

Expectations

In a decision for CS, according to the physicians and nurses in our focus groups, the patient's family is important. For family members it is sometimes very difficult to watch a loved one who is sedated, especially if the sedation extends for a long period of time. It is therefore deemed important always to properly inform the family of what continuous sedation involves and what can be expected to happen to their sedated relative to make sure that they know what to expect. But even when appropriate information has been provided, when medical practitioners feel that a sedation could cause the family distress, this works as a barrier.

> **Physician P**: We certainly do not find it ideal, a palliative sedation, because of the family's expectations and the fact that it can take some time, much longer than the family had imagined. That their father or mother or brother or sister or partner is lying there, unconscious in a coma, but still with physical discomforts and all the care involved... which is often difficult for the family, and we definitely do not promote this. We really try to ask because we're afraid of the disappointment, the fact that the patient, the family may not be able to cope, that it takes too long. So we try to discourage it more than we suggest it. Definitely not suggest it.

When the family is not adequately informed, according to the participants, this could lead to the family pressuring the medical professionals to speed up their relative's dying process.

> **Physician A:** You have to explain it very clearly to the family because if you don't, you really get into trouble. If you do not say clearly that it can even take a week, if you did not make that clear to the family beforehand, you will encounter some people who become almost aggressive and say 'well it's not easy with my job and I have to be able to plan when the funeral will be and that's when I want it to happen and can't you speed it up?'. You are, quite simply, being pressured by the family. That is why I always say, don't start with sedation if you have not made everything very clear to the family beforehand.

Existence and use of guidelines

Some nurses stated that the existence of guidelines made the use of CS easier for some physicians.

> **Nurse MT:** But in a euthanasia procedure it is required that a physician consults with the nursing team and the family, while for a palliative sedation there are no procedures, there are no guidelines. So precisely this profile of very dominant

hierarchical physicians matches very well with a palliative sedation, because there, they are master and commander and they don't have to consult anyone.

Moderator: So that's a completely different framework than the one surrounding euthanasia?

Nurse MT: That's right, that kind of physician and their choice of not performing euthanasia, but instead initiating palliative sedation and quietly increasing the dosage, we call that a 'sans papiers'[3] in our team. There's no procedure, there's no registration and it's all OK, the problem is solved.

Attitudes of medical practitioners involved in continuous sedation

The focus group participants considered the attitudes of physicians and nurses towards sedation and euthanasia to be a factor that could work as a facilitator to the use of the practice.

Nurse N: So in our ward, euthanasia is not possible. That's the physician's choice, whether we support it or not. But from time to time we have a patient with [a request for] euthanasia and then that always gets turned into a sedation.

Sometimes certain attitudes could also function as a barrier.

Nurse CL: I think life is important, but consciousness, for goodness sake, that's almost even more important and we should not easily interfere with that.

Possibility of alternatives

An important indication to initiate CS was said to be that no alternatives were possible. The physicians in the focus groups stressed that sedation could only be considered when it was the very last option.

Physician A: When you feel you have reached the end with other medication and other means, you stand with your back against the wall as a physician ... you can't offer anything else and you see that your patient is suffering immensely and this is your last way of making it dignified for her and her family.

[3] 'Without papers' - an expression normally used to refer to illegal immigrants.

Some nurses, however, questioned how this 'last resort' should be interpreted. They argued that even in cases where there are no medical alternatives, there might still be non-medical alternatives.

> **Nurse C**: And I have some questions about that. I think tackling the anxiety with medication is a possibility, but I think there are other options besides that. Sometimes, perhaps, making patients feel you are supporting them more, together with the family. Also guiding the family and giving support together to a dying person: spiritual guidance, psychological guidance, massages, presence, relaxation. There are, I think, other options.
> **Moderator**: You mean non-medical solutions?
> **Nurse C:** Non-medical solutions.
> **Nurse M:** Presence in all its forms, by involving yourself with people.
> **Nurse CL**: And that might be much more effective than a sedation, the fact that someone is standing behind you or beside you.
> **Nurse C:** Yes.

8.4 Discussion

This study analyses the insights and experiences of 21 medical professionals, from a balanced mix of settings, with continuous sedation at the end of life. In view of the nature of our research methods, we would caution against a generalisation of our results to CS practice as a whole or even to CS practice in Belgium. However, at the same time we believe our results represent more than simply reflections from a small group of caregivers. Thanks to the fact that we used experienced moderators and included participants from a balanced mix of setting, our study provides several valuable insights into which factors are likely to influence physicians in their choice for or against administering continuous sedation at the end of life.

In their reflections on what facilitates or constrains them in the use of continuous sedation, physicians and nurses gave a lot of attention to patients' needs as well as to their wishes.

First, all the nurses and physicians in our focus groups agreed that not every patient who asks for continuous sedation at the end of life should receive it. Certain criteria have to be met: (1) the patient must have a short life-expectancy and (2) must be suffering intensely. Medical practitioners are therefore more likely to use CS when they are convinced that the patient is in a state where she needs it. This could perhaps partly

explain why sedation is most often used very shortly before death. Research in Belgium indicates that in 56% of sedation cases, sedation lasted less than 48h (Chambaere et al. 2010).

Second, according to the physicians and nurses in our study, the use of CS is not only facilitated by patients' perceived needs, but also by a clearly expressed patient wish to be continuously sedated until death. So it seems that physicians and nurses are most comfortable in using sedation on patients who are clearly perceived to need CS *and* explicitly ask for it. This might be called the 'paradigm case', where, according to the participants, a choice for sedation is most likely.

However, the nurses and physicians in our focus groups also had a lot of questions regarding this paradigm case. As regards patient needs, it was often unclear when a patient actually needed CS, since, unlike with patient *wishes*, whether a patient *needs* CS is assessed by a physician, implying that different physicians may reach different decisions. For some nurses, purely existential suffering could be regarded as equal to physical suffering and could therefore sometimes be an indication for CS, whereas some physicians were more reluctant to use continuous sedation in these cases. Other nurses questioned whether patients who were said to need sedation might in fact be better helped with non-medical alternatives such as presence and/or spiritual guidance. Even though our focus group participants were aware of the Dutch national guideline which provides that continuous sedation should only be initiated as a last resort and for refractory symptoms, a judgment is still necessary as to whether in a specific case the patient's symptoms are indeed refractory[4] or whether continuous sedation is indeed the only available option, hence an element of subjectivity is unavoidable. In 2010, after the focus groups were held, a Belgian guideline for continuous sedation was published (Broeckaert et al. 2010). Like its Dutch counterpart, the Belgian guideline requires a physician's judgment by stressing that CS should only be used in patients with a short life expectancy and unbearable suffering from a refractory symptom that may be physical, purely existential or a combination of both, and that, if possible, there should be a request or consent from the patient or her legal representative.

Patients were said to request CS rarely. One of the main reasons that was given, was that patients were often not aware of the existence of CS. At the same time physicians were hesitant to mention the practice first for fear of unduly influencing the patient to

[4] By which are meant symptoms that are unresponsive to available treatment or for which available treatment has unacceptable side-effects.

choose CS. This then creates the rather awkward situation that a physician is waiting for the patient to request a practice she doesn't even know about. This may lead to sedation not being discussed, or discussed only very late in the disease trajectory when the patient is suffering severely and obtaining her consent has become problematic or even impossible, thereby deflecting decision-making to a third party (Battin 2008). As mentioned above, available research indicates that, in Flanders (Belgium) in 2007, a request was made by the patient in only 10% of all continuous deep sedation (CDS)[5] cases, and in another 20%, while there was no request, the patient had consented to CDS (Chambaere et al. 2010).

Another factor that was mentioned by our focus group participants as being of great importance, was the patient's family. Data from Flanders (Belgium) indicate that, while patients are often not involved in the decision to use continuous sedation (due to incompetency or other reasons), family members are involved most of the time, making them an important third party (Chambaere et al. 2010). This was confirmed in the focus groups. In some cases, it was said, families will exert pressure on the medical team to increase the dosage and to speed up the sedated patient's death, making the medical practitioners feel very uncomfortable. This is interesting since, in the absence of a patient request or consent, one might expect the family members to help determine what the patient would have wanted if she were competent, bringing the difficult cases as close as possible to the paradigm case.

Thus it seems that even though there is a paradigm case in which, according to the physicians and nurses in our focus groups, continuous sedation is clearly indicated and in which its use is perceived as comfortable, this paradigm case might be the exception rather than the rule. Moreover, deviations from the paradigm case may often be due to the physicians themselves, when they are unwilling to initiate a conversation about continuous sedation or when they initiate it too late. For incompetent patients, the family is frequently involved in decision-making, but after the sedation has been initiated, families were said to often be a hindrance when they put pressure on the medical team to speed up the process.

Accordingly, there might be reasons for medical professionals to try to approach this paradigm case as closely as possible, since such cases pose the least problems. This means placing more emphasis on patient consent, as recommended in a Belgian guideline published in 2010. In The Netherlands a guideline on continuous sedation that

[5] This research focused only on deep continuous sedation.

also stresses patient request or consent was published in 2005 and, after its introduction, patient involvement in decision-making rose (Hasselaar et al. 2009). One might hope the same will happen in Belgium, although it should be noted in this regard that the Dutch guideline has legal ramifications whereas the Belgian guideline does not (Griffiths et al. 2008). When patient involvement is impossible, the best way to approximate patient consent is to involve the patient's family to determine what the patient would have wanted.

Finally, another interesting finding that emerged from our focus groups, even though the moderators did not mention the topic of euthanasia, was that some physicians consider continuous sedation to be an alternative to euthanasia. One of the nurses used the term 'sans papiers' to refer to a case where sedation is used as a way to shorten life while at the same time avoiding all the requirements of due care that are obligatory when performing euthanasia, as well as the obligation to report, and thus avoiding scrutiny. Another nurse indicated that in her ward CS is even used on patients who have made a clear request for euthanasia. This confirms again that the issue of the relation between continuous sedation at the end of life and euthanasia is not merely debated in academic literature (Tännsjö 2004; Materstvedt 2012), but is also an important topic for physicians and nurses in their daily practice. This raises serious questions, since one of the reasons for legalising euthanasia in Belgium was that legalisation, together with an obligation to report, would make a practice which, before, was hidden, visible and susceptible to scrutiny. Some of the participants in our focus groups had many reservations about whether CS should be initiated without a patient request or with patients who have a longer life expectancy, but were less concerned about whether CS should be used as an alternative to euthanasia.

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Chapter 9
Similarities and differences between continuous sedation until death and euthanasia – professional caregivers' attitudes and experiences: A focus group study

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9.1 Introduction

In Belgium, numerous palliative care structures and services have been developed to provide high quality care for terminally ill patients (Keirse et al. 2009). Yet it is possible that patients in the final phase of their life suffer persistently and unbearably from refractory symptoms, i.e. symptoms unresponsive to available treatment. According to various guidelines, in such cases, continuous sedation until death can be considered (KNMG 2009; Broeckaert et al. 2010). Continuous sedation refers to the practice where sedation, i.e. the lowering of the patient's consciousness, is administered continuously until the time of death (Seymour et al. 2011). Continuous sedation can vary from mild to deep sedation (de Graeff & Dean 2007; KNMG 2009; Broeckaert et al. 2010; Swart et al. 2012). In the Flemish region of Belgium in 2007, its incidence was estimated to be 14.5% of all deaths (Chambaere et al. 2010). In the Netherlands in 2005, continuous sedation was given in 8.2% of all deaths and in the United Kingdom in 2008 in 16.5% (Rietjens et al. 2008; Seale et al. 2009; Anquinet et al. 2012).

Various guidelines state that continuous sedation at the end of life can only be performed when the patient has a very limited life expectancy (KNMG 2009; Broeckaert et al. 2010). Further, they stress that continuous sedation should be distinguished from euthanasia - i.e. the intentionally ending of life by administering medication at the explicit request of a patient-, explaining that continuous sedation is a way of proportionally alleviating the patient's refractory suffering and does not aim at the death of the patient (Deliens & van der Wal 2003). In Belgium as well as in The Netherlands, given the fact that euthanasia is legalised (Deliens & van der Wal 2003; Wet van 28 mei 2002 betreffende de euthanasie 2002), the guidelines regarding sedation address the issue of the differences between continuous sedation and euthanasia. A nationwide palliative sedation guideline has been introduced in 2005 (and revised in 2009) in the Netherlands (KNMG 2009). In Belgium however, a guideline was introduced only recently (December 2010), and after we conducted our study (Broeckaert et al. 2010). The goal of our study was to explore the attitudes and experiences of physicians and nurses in Flanders with the practice of continuous sedation until death. We therefore conducted focus groups. The focus groups were conducted at the preliminary stage of a larger international interview study (the UNBIASED study - UK Netherlands Belgium International Sedation Study), aiming at exploring clinical decision-making surrounding the use of continuous sedation until death and understanding the beliefs,

perceptions and experiences of (in)formal caregivers regarding this practice (Seymour et al. 2011).

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

9.2 Methods

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

Participants and setting

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

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

Two focus groups were held with physicians and two with nurses. Four to nine participants took part in each focus group. See Table 8.1 for their characteristics.

Table 8.1 Charactertics 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

***** In the home care settings, physicians included general practitioners, whether or not they were part of a palliative home care team. Nurses in the home care setting were always member of a palliative home care team.
†The number of times physicians or nurses have had experience with continuous sedation until death.
‡Missing: Focus group 1 Physicians *(In the professional career: n=1)*; Focus group 2 Physicians *(In the last year: n=1; In the professional career: n=1)*; Focus group 1 Nurses *(In the professional career: n=2)*; Focus group 2 Nurses *(In the professional career: n=3)*
§85 years, retired.
‖ Unknown: Focus group 1 Nurses *(In the last year: n=1)*; Focus group 2 Nurses *(In the last year: n=1; In the professional career: n=1)*

Procedures

The focus groups were held at Ghent University Hospital and lasted about two hours. They were led by experienced moderators (LD & JR, SS & JR or SS & RD). Notes were made by two observers (LA & KR). All participants gave their informed consent to the audio taping of the discussions. The moderators used a topic guide, consisting of open questions and a brief set of prompts (Box 8.1). This topic guide covered several themes: 1) experiences of the participants with various types of sedation at the end of life; 2) attitudes regarding continuous sedation; and 3) the medical situations in which continuous sedation is perceived to be more easy or difficult. Three vignettes were used to guide the discussion (Box 8.2). In each vignette, the presented patient had terminal breast cancer and suffered unbearably from untreatable physical symptoms despite receiving palliative care. The cases varied according to the patient's life expectancy (a few days versus 3 to 4 weeks), the performance of continuous sedation (deep sedation from the start versus titration of sedation according to symptoms) and the duration of the sedation (3 days versus 1 week). Socio-demographic characteristics were obtained from all participants (Table 8.1).

Data analysis

The recordings of the focus groups were transcribed verbatim and all data that could identify the participants were removed to preserve anonymity. We performed constant comparative analyses. First, all transcripts were read several times by a multidisciplinary team of researchers (JR, SS, LA, KR, LD). We identified the differences and similarities between continuous sedation and euthanasia as a major theme. We reread all text fragments concerning this theme, and discussed, designed and agreed upon a coding tree. All the text fragments were coded independently by LA and KR and the codes were independently checked by JR and SS. Differences in coding between the researchers were minimal and a consensus was always reached. Qualitative analysis software (NVivo 9) was used to organise the data. Finally, quotes were selected by LA, KR, JR and SS, and translated by SS working with a native speaker.

Box 8.1 Topic guide of the focus groups with physicians and nurses

Introduction

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

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

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

Part II: Understandings of and experiences with continuous sedation until death – Vignettes

Vignettes of cases of continuous deep sedation until death are presented via Powerpoint.

Questions per vignette:

1. Which term best describes this act? Why?

2. Would you act in the same way? Why (not)?

3. Do you have any experience with other situations or circumstances in which patients are continuously sedated until death?

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

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

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

Closing; answering questions; thanking the participants

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

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

Box 8.2 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 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.**

9.3 Results

Differences between continuous sedation and euthanasia

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

Preferences and requests

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Physician A; Home: Those are the situations that we encounter most frequently in practice. Someone ends up in a hopeless situation, with no clear consensus having been reached with the patient in advance about the possibility of performing euthanasia, of performing a technique to shorten life. Sometimes this argument [that there was no clear consensus] is abused by colleagues of ours […] who have kept postponing [any discussion with the patient about euthanasia] and then of course, the patient ends up with her back against the wall and then the patient

asks for euthanasia, but until then, they weren't listening to their patient and then they say 'yes, but now it is too late, because I can't arrange that [euthanasia] in such a short time'.

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

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

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

Decision-making

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

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

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

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

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

> **Nurse A; Home**: But in a euthanasia procedure it is required that a physician consults with the nursing team and the family, while for a palliative sedation there are no procedures, there are no guidelines. So precisely this profile of very dominant hierarchical physicians matches very well with a palliative sedation, because there, they are master and commander and they don't have to consult anyone.
> **Moderator:** So that's a completely different framework than the one surrounding euthanasia?
> **Nurse MT**: That's right, that kind of physician and their choice of not performing euthanasia, but instead initiating palliative sedation and quietly increasing the dosage, we call that a 'sans papiers' in our team. There's no procedure, there's no registration and it's all OK, the problem is solved.

Intention

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

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

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

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

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

When the distinction between continuous sedation and euthanasia may become blurred

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

Nurse F; Oncology: I'm always struggling with this. The transition. When do we talk about euthanasia, and when about sedation?
Nurse G; Home: No, euthanasia, that is clear ... that is very clear.
Nurse F; Oncology: I don't know, for me it is not so clear. I find it a bit eh ...
Nurse G; Home: Euthanasia is really [...] where someone is [...] giving a lethal injection at the request of the patient. Whereas sedation is just keeping someone asleep until maybe death follows.

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

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

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

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

Nurse I; Home: [I] think: 'Darn, we are doing it [increasing the dose] and it happens all the time in practice'. And that is very difficult for me. What do you have to do about the team? How can the team cope with the fact that yesterday the pump was on such and such a dose but today it is at a higher dose.
Nurse J; Palliative support team: If it is agreed in advance that we will increase, increase, increase the dose until the patient dies, then what is happening is not attempting to control the symptoms and allowing the patient to die. The intention then is to end life.

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

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

9.4 Discussion

Although the differences and similarities between continuous sedation until death and euthanasia were not specifically addressed in the questions in the focus groups, it emerged as an important theme in the accounts of the participants. Our study describes the similarities and differences between both practices as perceived by physicians and nurses in Flanders, Belgium. Sometimes the term euthanasia was used by both groups as an umbrella term, also including acts of life ending without a request of the patient. Many participants perceived differences between continuous sedation and euthanasia,

particularly with regard to preferences and requests, decision-making, and intention. However, some participants stated that the distinction between the two is sometimes blurred or even non-existent, especially when medication is increased disproportionally or when sedation is induced too early.

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

Euthanasia was legalised in Belgium in 2002 after more than a decade of intense societal debate galvanised by an opinion on euthanasia from the Belgian Advisory Committee on Bioethics as well as three years of debate in parliament (Deliens & van der Wal 2003). This end-of-life practice has increasingly been brought to the attention of caregivers and the general public, also by way of the media, and to this day, it remains an important issue of public debate (Meeussen et al. 2011). According to our participants, patients requesting euthanasia generally used more specific formulations, whereas continuous sedation was less often or less explicitly addressed by patients. It is possible that the practice of continuous sedation until death is less well-known among patients and their environment. Furthermore, it may also relate to the fact that a key condition for euthanasia is that the patient should make an explicit request, while such a request is not a prerequisite for the use of continuous sedation until death (although guidelines state that its use should be discussed with a competent patient or his/her representatives). Despite the fact that patients' and families' wishes were not always expressed clearly or specifically, the participants in our study stated that they deemed it

important to clarify these wishes and preferences through ample communication and discussion.

Besides the importance of discussing such far-reaching end-of-life decisions with the patient, consultation and discussion with other caregivers is deemed important too. For euthanasia, the physician must consult with a second independent physician as well as with the nursing team if applicable (Wet van 28 mei 2002 betreffende de euthanasie 2002). Various guidelines on sedation state that the members of the team involved in the care for the patient should be actively involved in decision-making (KNMG 2009; Broeckaert et al. 2010). If a physician doubts his/her own expertise concerning continuous sedation or finds it difficult to decide whether or not to initiate continuous sedation, the physician should seek specialist palliative care advice. Nurses in our study reported to be less often involved in decision-making for continuous sedation than for euthanasia. This is in line with the findings from another Belgian study: Inghelbrecht et al. found that there was no communication between the nurse and the physician about continuous deep sedation in 17.6% of the sedation cases (Inghelbrecht et al. 2011).

Although the majority of the respondents in our study considered continuous sedation and euthanasia as different practices at the end of life, some stated that the clear distinction between continuous sedation and euthanasia diminishes or may even disappear when medication is increased disproportionally or when sedation is induced too early. Some respondents described that in such instances, the physician's intention is or shifts to life ending. The focus group participants thus often considered the intention with which the action is performed as well as the outcome, pivotal in distinguishing continuous sedation from euthanasia, which is in line with the argumentation developed in Materstvedt (Materstvedt 2012). The finding that some respondents did not always find sedation and euthanasia to be always clearly distinguishable is also in line with other studies. In a study of Rietjens et al., some American nurses had difficulties with working on a 'fine line' between sedation and euthanasia (Rietjens et al. 2007). According to them, sedating a patient diminishes the patient's capacity to eat and drink, and as such will contribute to their death. A study concerning general practitioners of Anquinet et al. revealed that 2 out of 28 physicians perceived the use of continuous deep sedation as similar to euthanasia (Anquinet et al. 2011). This was the case when the patient had previously made a request for euthanasia. Other studies have also shown that physicians sometimes also administer sedatives when they intend to end life (Rietjens et al. 2004; Chambaere et al. 2010). An international study of Anquinet et al. that compared the practice of continuous deep sedation in Belgium, the Netherlands and the UK, found that in several cases, physicians who had indicated that they had performed continuous deep sedation until death also indicated that they had done so to end a patient's life (Anquinet et al. 2012). However,

these studies do not report on the types and dosages of drugs administered during the performance of continuous deep sedation until death. Because it is known from studies about the effect of morphine on patients' life expectancy that physicians might overestimate the life-shortening effect of such medications (Morita et al. 2001) these studies should be interpreted cautiously.

Guidelines distinguish the use of continuous sedation until death from drug-induced ending of life (this is referred to as euthanasia in the case of an explicit patient request) by referring to the physicians' intention as well as to the outcomes of the physicians' acts, therefore referring to similar concepts as our focus group respondents. More specifically, the guidelines state that the physician's intention while applying continuous sedation should be to relieve suffering through the lowering of consciousness, while the physician's intention while applying euthanasia is to relieve suffering through the ending of life by the administration of a lethal dose of medication (KNMG 2009; Broeckaert et al. 2010). They further state that 'the physician's act should reflect this intention, meaning that the dosages and combinations of medication should be administered in proportion to the specific suffering of the patient that the physician wants to alleviate' (Broeckaert et al. 2010, author's own translation from Dutch). In addition, the guidelines say that 'Continuous, deep sedation differs from euthanasia in that its aim is not to shorten life. Indeed, there is no evidence that such sedation, if carried out in accordance with good medical practice, does shorten life' (KNMG 2009, 66). Therefore, they state that sedation can only be used for patients with a life expectancy of at most a few days to one week (Belgian guideline), or to 2 weeks (Dutch guideline), because otherwise patients would die as a result of the sedation, that is, through dehydration, since both guidelines recommend to withdraw the administration of artificial hydration when this is considered to be medically futile (KNMG 2009; Broeckaert et al. 2010).

We want to point to two caution remarks here. First, on the basis of our qualitative data we cannot draw conclusions on the frequency of physicians' use of sedation with the intention or the outcome of shortening life. Second, there is ample ethical debate and no clear consensus about the differences and similarities between sedation and euthanasia, and several authors claim different borders (Rady & Verheijde 2010; Materstvedt 2012). In this paper, we describe the experiences and attitudes of our focus group respondents. Having said that, it is clear that the situations described by the respondents are clearly not always in line with guideline recommendations (KNMG 2009; Broeckaert et al. 2010). This might in part be explained by a lack of knowledge about the circumstances in which sedation can be used as well as the way it should be performed properly. The Belgian sedation guideline has been published in September 2010, after the performance of our focus group study. Also, it is possible that physicians

perceive continuous sedation as part of regular medical treatment and therefore, for example, do not feel obliged to talk the decision for sedation through, e.g. with nurses involved in the care for the patient or palliative care expert teams.

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

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Part 4

Conclusions

Chapter 10
Conclusion

10.1 Research questions

The research questions for this dissertation were:

1) In what ways is continuous (deep) sedation until death portrayed?

1.1) Are these portrayals successful?

1.2) Why are some of these portrayals successful?

1.3) What is the ethical impact of these portrayals?

2) What is the ethical validity of these portrayals?

2.1) Do these portrayals survive ethical scrutiny?

3) In what way is the practice of continuous (deep) sedation until death experienced by medical professionals?

3.1) Does this experience match the portrayals discussed when answering research question 1 and 2?

In this dissertation I have attempted to answer these research questions by setting the stage (chapters 1, 2, and 3), by discussing the most common portrayals of CS (chapters 4 to 7), and, finally, by partly using this knowledge to elicit medical practitioners' experiences with and attitudes towards the practice of continuous sedation at the end of life (chapters 8 and 9).

10.2 Research questions 1 and 2

The key issue concerning CS, which has been stressed repeatedly throughout this work, is that there is a lack of agreement on how we should define continuous sedation until death. This makes it possible for people to depict CS in selective ways, something which,

as I hope to have shown, frequently happens. These depictions often serve a purpose, be it as part of a coping strategy, or as a strategy to make the practice ethically less or more acceptable. Some depictions have been discussed separately, but there are many elements that can be said to be common to all or many of these portrayals. These common elements give insight into how these portrayals work.

Language used to discuss CS

What most portrayals of CS share is the manner in which they use certain concepts to their advantage. As has been made clear throughout this dissertation, the language that is used is often imprecise and/or ambiguous.

The concept of CS itself

The concept of CS is itself already imprecise and ambiguous, as it has no generally accepted definition (as was extensively discussed in chapter 2). Moreover, as I hope to have made clear throughout this work, there is currently no value-free way of defining continuous sedation at the end of life; the concept means different things to different people. So while I have at times criticised some definitions as being overly normative, authors who give an explicit definition at least affirm the lack of a univocal definition and try to create some clarity in today's conceptual maze.

Furthermore, I would like to stress again that I do not consider the criticised definitions to be 'wrong', as they are often merely statements about how a certain author intends to use the concept of CS or what that author means when she refers to CS. Everyone is free to understand and/or use a word or concept in a certain way if this is done transparently.

Nevertheless, there may be reasons to prefer some definitions over others. Although most definitions are not necessarily 'wrong', they may be improper or misleading, by, for example, having a deliberate air of being descriptive, whilst actually incorporating many normative elements. I consider an improper definition to be one that hinders or pre-empts the ethical discussion about the concept that is defined. I have argued for a definition of CS that includes what actually occurs in practice (as is made clear from existing research) and permits an honest ethical discussion.

Ambiguous language

What many of the depictions or portrayals of continuous sedation share is a language use that is sometimes ambiguous. Some of the words and concepts commonly used to talk about sedation can have both a descriptive meaning and a normative/moral

meaning, and it is often not clear which meaning the words and concepts are given by a certain author. In the fourth chapter of this thesis, it was shown that death after continuous sedation is, by many authors, called 'natural'. This seems to be a descriptive concept, but it has a long history of being used as a moral concept conveying ethical acceptability. By applying this label to death after continuous sedation, this ambiguity can be used to blur the line between description and normative judgement. An example of this can be found in an article by Claessens et al. where the perceived naturalness of death after CS is turned into an argument for the withdrawal of artificial nutrition and hydration (ANH):

> If a patient shows signs of imminent death (e.g., loss of appetite, decreased food/fluid intake) before sedation, then it seems irresponsible and unethical to hamper the natural dying process by administering artificial food or fluid during sedation. (Claessens et al. 2008, 328)

The argument here seems to be that CS with withdrawal of ANH is natural (and therefore good) and that it is in fact the provision of artificial nutrition and hydration that endangers the natural dying process and should therefore be avoided.

This blurring of description and normative judgment can also be seen in the concept of 'normal medical practice', which, as chapter 5 shows, is also used to refer to sedation at the end of life. The concept is used in the Dutch guideline on continuous sedation and is a descriptive and legal concept which refers to a practice that physicians are legally allowed to perform. Like 'natural', however, the concept seems to convey a message of ethical acceptability, and, in the literature, the term has indeed been used to convey this message.

Other examples have been discussed in this thesis, such as the idea that sedation is 'legal'. Even if continuous sedation is legal, that does not necessarily imply anything with regards to its ethical desirability, as is sometimes argued.

A final example discussed in this disseration is that of 'proportionality'. As shown in chapter 5 and 7, there seems to be some degree of consensus that in continuous sedation at the end of life sedatives should be administered *in proportion* to the severity of a patient's symptoms. In this way, proportionality is a matter of fact that can be checked using various measuring techniques. At the same time, proportionality is also an ethical principle that is used to justify certain acts by weighing relative harms and benefits against each other. Chapter 6 showed that proportionality is also one of the key conditions for the doctrine of double effect to apply. So, again, when the claim is made

that sedation at the end of life is a proportionate response to a patient's suffering, it is often unclear whether 'proportionate' is used factually or normatively.

Misleading language

In my view, not only is it common for imprecise and ambiguous language to be used when continuous sedation at the end of life is discussed, but the descriptive/normative concepts discussed earlier are often used in a way which conflicts with their factual meaning. So regardless of the problems of moving from factual concepts to normative approvals or disapprovals, the factual concepts often do not apply unproblematically. Chapter 4 contains a discussion of why I believe 'natural' does not apply to continuous sedation. In chapter 7, I attempted to show why it is problematic to call continuous sedation 'proportional' to a patient's symptoms, unless one actually measures the sedated patient's level of consciousness in a valid and reliable way. Calling sedation proportional while not measuring is, at best, misleading. The way in which the concepts of 'legal' and 'normal medical practice' relate to continuous sedation, as was discussed in chapter 5, is somewhat different as their use in discussing continuous sedation is not clearly wrong. On the other hand, neither is their use problem-free. The legality of continuous sedation is open to debate, as some authors consider the practice clearly legal, while others question whether it is, or at least point out that its legality is not beyond doubt.

Hypotheses regarding the success of the portrayals discussed

Claiming that CS is portrayed in a selective way, using language that is at times ambiguous and/or misleading, inevitably raises the question of who is doing the portraying. Is there a deliberate ploy to portray sedation in a certain way, thereby sanitising the practice and making it ethically more acceptable?

It is, I believe, not particularly interesting to answer this question on an individual level. For example, not every patient, doctor, or relative who refers to death after CS as a 'natural' death would be doing this as part of a deliberate strategy. Nevertheless, on a more general level one *can* see a tendency to portray CS in a selective way, for example in the media, in current guidelines on CS or in international literature. Some of these portrayals are then picked up, for example by medical practitioners and patients, and become part of the accepted understanding of CS. The interesting question to pose is therefore why certain portrayals (e.g. the portrayals discussed in this dissertation) are more successful and are more widely accepted. Most of the answers to that question are, of course, hypothetical, but I nevertheless believe that the 'popular' portrayals share certain characteristics that make them appealing to a large number of people.

First, what these portrayals share is that they may appeal to medical practitioners. It is important to realise that discussing continuous sedation is different from, for example, discussing the morality of a technological intervention that is many years from being realised. Studies show that physicians often use continuous sedation for terminally ill patients with severe suffering. Medical practitioners have to make such far-reaching treatment decisions on a daily basis and therefore have an interest in justifying the use of continuous sedation to themselves. This could explain why practitioners may feel more comfortable in thinking about sedation as a 'normal medical practice' and as a proportionate response to extreme suffering, as this places CS on a par with other medical decisions they must make in their everyday practice. Moreover, as was explained in chapter 4, portraying death after CS as a natural death diminishes the physician's agency and therefore her responsibility, in the same way as considering CS to be a 'last resort' does. As a coping strategy for a difficult decision, it is quite understandable that medical professionals may like to think about CS in a non-controversial way.

Second, and relatedly, there is the issue of the patients' relatives. Medical professionals often have to explain the practice of CS to relatives who are in a vulnerable position as they are about to lose a loved one. The results of the focus group we conducted confirmed that communicating with relatives is often difficult. It is thus understandable that physicians and/or nurses may prefer to talk about sedation in a non-controversial way, for example by explaining that the patient will be sleeping, rather than by saying that she will be kept in a permanent coma. In this way, certain portrayals could be perceived as helping relatives to cope with the loss of their loved ones.

There is a third reason why some portrayals of CS may be appealing to medical professionals. We know that, despite advances in medicine and palliative care, many people at the end of life are confronted with severe and untreatable symptoms that give rise to unbearable suffering. Medical practitioners have a duty to relieve patients' suffering as much as possible (i.e. the ethical principle of beneficence), so they have an interest in being able to use the best and/or most effective techniques to relieve this suffering. In some countries (Belgium, The Netherlands, Luxembourg, and some states in the US), physicians can resort to euthanasia or physician-assisted suicide (PAS) to relieve the unbearable suffering of those patients who explicitly ask for it. In most countries, however, physicians do not have the option of using euthanasia or PAS. These physicians might therefore have an interest in retaining the ability to use continuous sedation as the most far-reaching practice to reduce severe patient suffering. Of course, physicians in countries that have legalised euthanasia and/or physician-assisted suicide may also have an interest in CS being allowable, as many patients do not want to request

euthanasia or PAS or are no longer competent and so can no longer opt for euthanasia or PAS.

Fourth, opponents of legalised euthanasia may also have an interest in depicting continuous sedation as acceptable. If they can show that continuous sedation can provide an alternative to physician-assisted suicide and/or euthanasia, while not being susceptible to some of its problems, such as for example risk of abuse, slippery slope and lying outside of the realm of medicine, they can make an argument for allowing sedation and not legalising PAS and/or euthanasia. This issue was discussed in chapter 5.

As I have argued, many reasons may lie behind the fact that some portrayals of CS are more widely accepted than others. As discussed, not all selective portrayals of CS are deliberate attempts to deceive, but they may often form part of an understandable coping strategy for medical practitioners. Some of these portrayals may have no underlying bad intent, nonetheless we still need to be aware of what their effects might be.

First, as was said, it is understandable that physicians and nurses feel comfortable in portraying CS in an unproblematic way, but we have to be careful not to turn a blind eye to aspects of CS that *are* controversial. Throughout this dissertation I have tried to point out what some of these controversial aspects might be. A coping strategy for physicians should not lead to a silencing of all ethical discussion and debate.

Second, it is unclear to me that portraying CS as a natural death, as 'normal medical practice' or as a preferable alternative to PAS does always help relatives to cope. For one thing, this might simply be the medical practitioner's perspective as to what she believes will help relatives to cope, and this perspective could be overly paternalistic. Not every relative will need a sweetened version of CS to help her cope. Furthermore, portraying CS to a relative as being unproblematic might have an opposite effect once sedation is initiated. The physician may build up certain expectations that cannot be met when sedation is actually performed. A good example is 'sleep'. When a physician says to someone that her relative will sleep and then die a natural death, this might convey certain images of a quiet, peaceful death, while in reality the patient may seem to wither away within a time span of a week or more (e.g. showing a dramatical weight loss, changing colour, etc.). This could actually cause more distress than had the relative been warned beforehand that watching a sedated loved one on the trajectory to death would not always be as comfortable as the 'sleep then peaceful, natural death', picture might suggest.

Third, although coping mechanisms might play their part in the popularity of certain portrayals, this does not change the fact that some people deliberately portray CS in ways that suggest its ethical acceptability elective fashion. Some of the opponents of legalised euthanasia and/or PAS fall into this category. We need to bear this in mind.

10.3 Research question 3

The focus group study reported in chapters 8 and 9 reports the experiences of physicians and nurses with continuous sedation until death. Both chapters showed that medical practitioners often have strong views on the practice of CS. Most had a clear idea of which factors influenced their decisions to choose CS, and most also clearly distinguished the practice from euthanasia. Generally speaking, it is clear that the way in which these medical practitioners discussed CS accords well with the standard view as can be found in many international guidelines, such as the Dutch National guideline. Interestingly enough, although a Flemish guideline was only published after the focus groups were held, the recommendations made in that guideline also match very well with what was discussed in the focus groups. The Flemish guideline stresses that sedation can only be initiated when life-expectancy is short, and when a patient's suffering is severe. Furthermore, where CS is initiated, it should always be administered proportionally, and as a last resort. Finally, the Flemish guideline (just like its Dutch counterpart) explicitly mentions that CS should be distinguished from euthanasia on the basis of intention, something which was also emphasised by the focus group participants (see chapter 9).

Accordance with findings from research question 1

Another important finding is that the actual perceptions of physicians and nurses match very well with many of the theoretical ethical reflections about the portrayals of CS. The focus group study supports and partly confirms the arguments made in the first part of this dissertation. Chapter 8 shows that physicians and nurses often have a good idea of which factors could make a decision to use CS psychologically easier. We have dubbed this the 'paradigm case', and this case accords nicely with the common portrayals as discussed in the theoretical chapters. For example, many of the participants in our focus groups stressed that CS should only be initiated when there are no alternatives left, i.e. when CS is a last resort option. Chapter 5 showed how this is also a common element in the portrayal of death after CS as 'natural'. Moreover, participants

in the focus groups stressed that CS could only be considered when a patient is suffering severely and has a short-life expectancy. This is an element of a portrayal of sedation as a proportionate response to severe suffering, since only when suffering is severe enough, can taking away a person's consciousness be considered proportionate. Chapter 9 shows that the focus group participants also stressed that CS is distinct from euthanasia, for example since in CS one does not *intend* to kill, which one does in euthanasia. This of course perfectly fits with the portrayal of CS as a practice that can be justified by the Doctrine of Double Effect.

The empirical findings also accord well with the conclusions of many theoretical chapters, namely that some portrayals of CS are problematic. Indeed, the focus group participants seemed to acknowledge that there are sometimes cracks in the way sedation is depicted. Chapter 8 showed that although there is such a thing as a paradigm case where CS is indicated and choosing it is fairly easy, this case was said to rarely occur. Some nurses questioned how the idea of a 'last resort' should be interpreted, and they found it difficult to always maintain that CS is the only alternative, as there might often be non-medical alternatives. There is also the issue of existential suffering. Some participants questioned whether this could be an indication for CS (i.e. whether reducing consciousness could ever be proportionate to refractory existential suffering). In chapter 9 it becomes clear that, although CS can often be distinguished from euthanasia, there are cases where the boundaries become less clear. It is therefore difficult to maintain that CS is *always* distinguishable from euthanasia.

Thus, the data gathered for this dissertation support the idea that the portrayals of sedation that were discussed are widely used and could even be claimed to serve as the default position on sedation, but that this is not always a perfect fit with reality. Some cases clearly do not fit the standard view on sedation, for example cases where sedation is initiated early or cases where a doctor intends or co-intends CS to shorten life. This only strengthens the conclusion of this dissertation, namely that we should always be attentive to problematic elements of CS or problematic cases of CS.

10.4 Contribution of this work

Much has been written concerning sedation, which, especially in the last few years, has become something of a hot topic. Witness to this is the fact, that when the article chapter 5 in this dissertation is based on was published in the *American Journal of Bioethics*, this elicited no less than 13 comments. More striking than the number of

comments, was how divergent they were, with some commentators attacking every aspect of our article, while others were even looking to extend our argument further.

The contribution of this dissertation is that it is an attempt to identify issues concerning CS that are stressed most often in the growing literature on the practice, and to critically evaluate them. It is an attempt to disperse some of the fog surrounding CS. For example, though it is often stressed that death after CS is a natural death, this was mostly merely assumed. So not only was there little analysis of what it would mean for death after CS to be 'natural', it was almost never even recognised as being an important feature of CS. In chapter 4, I isolated the claim that death after CS is a natural death, analysed what it implies, and whether it survives ethical scrutiny. The same goes for the argument of preferable alternative discussed in chapter 5, the justification of CS using double effect reasoning in chapter 6, and the principle of proportionality in chapter 7. Though these issues pervaded the international literature, they were rarely discussed as such, and it was only by recognising them and discussing them as separate claims, that it became clear that they were untenable. This, I believe, is an important contribution of this dissertation.

A different contribution, is that this dissertation combines ethical reflection with qualitative research. Good ethics is bolstered by good data, whereas good research needs good ethics, so I attempted to combine the role of ethicist with that of the empirical researcher. As already stressed in the previous section, the ethical reflection in this dissertation cannot be separated from the qualitative research; they are mutually dependent and supportive.

10.5 Recommendations for further research

UNBIASED

Currently I am involved in an cross-national interview study, namely the 'UK, The Netherlands, Belgium International Sedation Study (UNBIASED)', the results of which are in the process of being analysed, and could therefore not yet be reported.

As the name suggests, this study is being conducted in the UK, The Netherlands, and Belgium. For each country we included cases of adult patients with a cancer diagnosis who died after having received continuous sedation at the end of life.[1] For each case we tried to interview the physician, nurse and relatives who were most heavily involved. These were semi-structured interviews which were guided by an aide-memoire and focussed on the interviewees' experiences in the particular case they were included for, but which also included some general questions about other experiences and the interviewees' attitudes towards CS.

Cases were included in three settings: the home care setting; the palliative care setting; and the regular hospital setting. The inclusion period for this study ran from January 2011 to May 2012. During this period we included 82 cases (22 UK; 35 NL; 25 BE) involving 54 physicians[2] (17 UK; 22 NL; 15 BE), 59 nurses (25 UK; 27 NL; 7 BE), and 33 relatives (8 UK; 14 NL; 11 BE).

All the interviews were recorded electronically and later transcribed verbatim, deleting all data that could potentially lead to the identification of the participant. For the analysis, a grounded theory type method was used, having codes emerge from the data, and later grouping codes together to create a coding tree. This was always done separately by at least two researchers and later combined into a final coding tree.

The extensive research protocol has been published in *BMC Palliative Care*. In this publication the methods of the study are explained in full. Although the data is not yet fully analysed, it is clear that what has been analysed confirms the findings in my dissertation. Issues such as proportionality, intention, and the naturalness of dying after CS are common themes in the interviews. Due to its cross-national character (something the focus groups lacked), the UNBIASED study will also make it possible to identify differences in the way in which sedation is portrayed in different countries. Issues such as, for example, proportionality, seem to be stressed more often by British doctors than

[1] We gave no definition for 'continuous sedation at the end of life', and we avoided using the concept as we believed this might bias the physicians in the cases they would hand us. We therefore gave all cooperating physicians a document containing a number of questions. We included all cases where the physician had indicated that the patient had a cancer diagnosis, was older than 18, had died, and had received sedative medication until the time of death (in whatever dosage).

[2] Some physicians and nurses were interviewed on more than one case, so that there are fewer included physicians than there are cases. To ensure the diversity of the sample, no physician or nurse was interviewed more than three times.

by Flemish doctors. This study thus represents an important next step in furthering the knowledge of continuous sedation at the end of life.

Strong clinical evidence base for sedation

A great deal more research on continuous sedation is still needed. Lack of a sound evidence base is a general problem for palliative care research. This could be partly due to the fact that palliative care is a relatively new branch of medicine, but, perhaps, could also be partly due to the fact that research in the field of palliative care is sometimes perceived as ethically problematic as it involves research with palliative and/or dying patients. More research is therefore needed on palliative care in general and not just on continuous sedation.

However, particularly for CS, I would recommend that research be done into the clinical aspects of continuous sedation. Guidelines such as the Dutch national guideline and the Flemish guideline make concrete recommendations for the types of drugs to be used for CS, and the dosages in which these drugs should be used. However, the choice of drugs and dosages is not supported by much clinical research, but rather is based on medical practitioners' experiences. Very interesting quantitative research is available on which drugs are used by physicians when performing CS. From this it is concluded that benzodiazepines are being used more and more frequently for continuous sedation, something which is presumed to be a good thing, as these drugs are recommended as the drug of choice.

However, as was explained in chapter 7, there is almost no research into the effects of sedative drugs on palliative and/or dying patients' consciousness. That a certain type of drug is used does not guarantee that it is always the right drug to use, that it is used properly, or that it has the right effect. It therefore remains uncertain what effect will follow in any particular case from the use of, for example, the drugs and dosages recommended in the Dutch and Flemish guidelines. As both guidelines claim 'proportionality' to be of great importance, research needs to be done in this respect.

An example of such a research study would involve the monitoring of sedated patients' consciousness using a physician's assessment of the depth of sedation, currently existing sedation scales, and techniques such as Bispectral Index monitoring. A study such as this would be valuable for two reasons. First, it could give us an insight into the actual effects of benzodiazepines (and other drugs) on palliative and/or dying patients. Second, by combining the results of the different measuring techniques, it would also be feasible for the first time to gain insight into whether clinical assessment and sedation

scales match well with more objective techniques such as electroencephalography or BIS monitoring. The result might be that they accord well, which would then provide a more solid evidence base for the use of clinical assessment and/or sedation scales. However, the result might just as well be that large differences exist between the techniques, in which case the least invasive and most effective sedation assessment technique should be identified.

10.6 Recommendations for the ethical debate

In this dissertation I have tried to further the debate on continuous sedation by showing that some common portrayals of sedation as an unproblematic practice cannot be justified for all cases of continuous sedation. As such, it is a plea for intellectual honesty. This, in my opinion, is the only way to further the thinking on sedation.

Of course, as has been stressed repeatedly throughout this dissertation, many cases of continuous sedation are unproblematic, and CS can be a good way to relieve suffering at the end of life. I therefore have no issues with the practice of CS in general, but I continue to stress that some forms of CS (i.e. deep sedation, or sedation without artificial nutrition and hydration) pose ethical issues that should not be ignored or reasoned away.

Most of the analyses in this dissertation were aimed at showing why a certain depiction of CS was not correct, or at least not always correct. More ethical debate is required to go from deconstructing the current standard view on sedation to building up a new coherent framework to reflect upon sedation. I hope and believe that this dissertation has offered the first steps towards such a new framework.

Nederlandstalige samenvatting

Inleiding

Ons hedendaagse sterven is fundamenteel beïnvloed door veranderingen en vooruitgangen in de medische wetenschap. Hoewel sommige patiënten nog snel en pijnloos sterven, komt dit volgens onderzoek minder en minder vaak voor. Onderzoek toont bijvoorbeeld aan dat in 2007 slechts ongeveer 31% van alle overlijdens in Vlaanderen kon bestempeld worden als een 'plots' overlijden (Bilsen et al. 2009). Dit betekent dat meer dan twee derde van alle personen die dat jaar stierven een langer stervensproces had. Ondanks goede palliatieve zorg, gaat dat langer proces, spijtig genoeg, ook vaak gepaard met een zekere hoeveelheid lijden (Steindal et al. 2011). Bij sommige patiënten is dit lijden ten gevolge van een aantal symptomen van zodanige aard dat het niet meer reageert op 'gewone' palliatieve zorgbehandelingen. In zo'n omstandigheden is het een mogelijkheid om het bewustzijn van de patiënt in de laatste dagen zodanig te verlagen dat de patiënt geen last meer ondervindt van de symptomen die zijn/haar lijden veroorzaken. Deze praktijk wordt ook wel continue sedatie aan het levenseinde (CS) of palliatieve sedatie genoemd en vormt het onderwerp van deze doctoraatsdissertatie.

Onderzoek toont aan dat deze praktijk vandaag de dag frequent wordt gebruikt, namelijk bij ongeveer 14% van alle stervende patiënten (Chambaere et al. 2010). Toch is de praktijk het onderwerp van een heftig juridisch en ethisch debat (van Delden 2007).

Juridische status

De wettelijkheid van CS is een eerste element dat ter discussie staat in de internationale literatuur. Sommigen beschouwen CS als 'normaal medisch handelen' dat valt onder de categorie van doorgedreven symptoomcontrole (iets wat bijna overal juridisch is toegestaan) en daardoor zelf ook wettelijk toegelaten is (bv. KNMG 2009). Anderen

hebben hier ernstige bedenkingen bij omdat, volgens hen, CS een zeer verregaande beslissing is, aangezien het zeer vaak neerkomt op het permanent onbewust maken van een patiënt. Men zou dit kunnen beschouwen als het toebrengen van ernstige schade, waardoor de juridische status van sedatie verre van zelfevident is (bv. Delbeke 2013, *te verschijnen).*

Ethische consensus

Wat betreft de ethische aanvaardbaarheid van CS kan men zich niet van de indruk ontdoen dat er schijnbaar enige vorm van consensus bestaat dat sedatie een gerechtvaardigde methode is om extreem lijden aan het levenseinde te bestrijden. Deze consensus wordt bevestigd in meer en meer richtlijnen rond sedatie die worden opgesteld. Deze richtlijnen komen vaak sterk overeen en schetsen een standaardbeeld van hoe CS zou moeten uitgevoerd worden. Bij het continu sederen, zo stellen de richtlijnen, (1) moet er een verzoek zijn van de patiënt of zijn wettelijk vertegenwoordiger, (2) mag er geen intentie zijn het leven van de patiënt te bekorten, (3) moet sedatie het 'laatste redmiddel' zijn om het lijden draaglijk te maken, (4) moet de patiënt een korte levensverwachting hebben en (4) moet de sedatie proportioneel zijn aan het lijden dat de patiënt ervaart. Vele richtlijnen stellen dat sedatie enkel mag worden toegepast bij symptomen die niet meer op een andere manier behandeld kunnen worden, de zogenaamde 'refractaire' symptomen. Als aan deze criteria wordt voldaan, zo suggereren de meeste richtlijnen, is sedatie onproblematisch.

Echter, dit standaardbeeld van CS als een onproblematische praktijk staat ook ter discussie. Vele richtlijnen beschrijven de praktijk van sedatie precies zo *omdat* ze sedatie naar voren willen schuiven als een praktijk die weinig ethische problemen stelt (Janssens et al. 2012). Toch zijn er nog vele ethische vragen te stellen

Levensbekorting

Vaak wordt gesuggereerd dat continue sedatie op geen enkele wijze het leven verkort. Voor deze claim wordt verwezen naar een aantal publicaties die precies dat zouden aantonen (bv. Sykes & Thorns 2003). Toch zijn hier vele vragen bij te stellen. Vele artsen en verpleegkundigen blijken er van overtuigd dat CS weldegelijk het leven verkort (Chambaere et al. 2010). Bovendien, zelfs als er geen levensverkorting zou zijn, neemt men bij sedatie sowieso permanent alle bewustzijn weg, iets wat voor velen gelijkstaat aan de dood aangezien de patiënt vanaf het moment van sedatie geen enkele ervaring meer heeft: positief noch negatief.

Vocht en voeding

Vaak wordt gesuggereerd dat het wegnemen van vocht en voeding bij een gesedeerde patiënt een beslissing is die volkomen losstaat van de beslissing tot sedatie. Echter, zeer vaak worden beide beslissingen samen genomen. Bovendien verandert het de gehele sedatie als vocht en voeding ook worden onthouden. Een sedatie zonder vocht en voeding kan nooit langer duren dan twee weken (aangezien dat de periode is waarin de patiënt zou komen te overlijden aan uitdroging) en is levensverkorting bovendien veel waarschijnlijker.

Proportionaliteit

In de literatuur wordt gesuggereerd dat CS minder problematisch is, omdat het altijd wordt toegediend in proportie tot het lijden van de patiënt. Bij veel lijden wordt de patiënt zeer diep gesedeerd, terwijl bij minder lijden het bewustzijn van de patiënt in mindere mate verlaagd wordt. Echter, hoewel men beweert proportioneel te handelen, wordt het bewustzijn van een patiënt onder continue sedatie amper gemeten, waardoor het onduidelijk is hoe diep de patiënt gesedeerd is. Als er al meettechnieken worden gebruikt is dit veelal zuiver klinische observatie of het gebruik van sedatie schalen, maar deze zijn invasief (de patiënt moet worden gepord of geschud) en niet echt betrouwbaar. Het is dus perfect mogelijk dat schijnbaar proportioneel gesedeerde patiënten in feite te diep of te licht gesedeerd zijn. Aangezien ze zelf niet meer kunnen communiceren is het uiteraard volslagen onmenselijk indien deze patiënten nog lijden, maar het niet meer zelf kunnen berichten.

Deze dissertatie

Zoals duidelijk wordt uit de vorige secties, zijn er nog vele ethische vragen rondom continue sedatie en deze vormen het onderwerp van deze dissertatie. De concrete onderzoeksvragen zijn:
1) Hoe wordt CS voorgesteld in de internationale literatuur?
2) Wat is de ethische waarde van deze standaardvoorstellingen?
3) Hoe zit het met de ervaringen van artsen en verpleegkundigen die sedatie gebruiken?

Hoofdstuk 2

In dit hoofdstuk wordt ingegaan op een van de belangrijkste kwesties rond continue sedatie aan het levenseinde, namelijk de definitie ervan. Er bestaan namelijk geen eenduidige definitie van CS en de term roept verschillende dingen op bij verschillende mensen. Er bestaat een reusachtige hoeveelheid aan definities. Sommigen daarvan zijn erg breed en definiëren CS als 'sedatie tot de dood volgt' (van Delden 2007, mijn vertaling). Andere definities contrasteren hier erg sterk mee en spreken enkel over CS wanneer het gaat om gevallen waar het verlies van bewustzijn de bedoeling is van de arts, wanneer het wordt gebruikt bij stervende patiënten, wanneer het de bedoeling heeft om onbehandelbare symptomen weg te nemen of wanneer het ethisch aanvaardbaar is (Cherny & Radbruch 2009).

Ik argumenteer dat het niet correct is om een te nauwe definitie van CS te hanteren. Immers, wanneer men zich in zijn definitie beperkt tot de ideale en onproblematische gevallen van CS en later besluit dat CS ideaal en onproblematisch is, begaat men een cirkelredenering. De enige uitweg om een grondige ethische analyse mogelijk te maken is het gebruik van een brede definitie. Mijn definitie is: *continue sedatie is de praktijk waarbij men sedatieve medicatie toedient die resulteert in een vermindering of een wegneming van het bewustzijn van een patiënt tot de dood volgt*.

Aangezien deze definitie erg breed is, blijft het belangrijk voor een goed en genuanceerd debat om verschillende types van CS te onderscheiden. Sedatie kan, bijvoorbeeld, zowel toegediend worden op verzoek van de patiënt als zonder verzoek en dit maakt, ethisch gezien, een groot verschil. Ook, CS kan uitgevoerd worden met onthouding van vocht en voeding of met toediening van vocht en voeding en kan zowel diep als licht zijn. Ook dit maakt een belangrijk verschil in de ethische evaluatie.

Hoofdstuk 3

Dit hoofdstuk behandelt vele van de issues die hierboven reeds werden aangehaald. Continue sedatie wordt vaak naar voren gebracht als een ethisch correcte manier om lijden weg te nemen en een schijnbare consensus wordt verdedigd. Desalniettemin blijven er vele vragen bestaan rond het gebruik ervan.

Een van die kwesties is het toedienen van vocht en voeding, al eerder aangehaald in deze samenvatting. Sommige auteurs zien het als een compleet verschillende beslissing, maar dit heeft, naar ik argumenteer, vaak enkel tot doel om CS minder problematisch te uitschijnen. Immers, wanneer iemand lange tijd gesedeerd is zonder dat er op

kunstmatige wijze vocht en voeding worden toegediend, is het minder duidelijk dat het leven in dit geval niet werd verkort.

Een ander issue is de betrokkenheid van andere partijen (buiten de arts en de patiënt) bij sedatie. De rol van de verpleegkundige is vaak onduidelijk en dit kan leiden tot onzekerheden bij verpleegkundigen. Ook naasten van gesedeerden zijn vaak betrokken partij en onderzoek toont aan dat ook zij vaak worstelen met bepaalde elementen van sedatie, bijvoorbeeld de onzekerheid over hoe lang hun geliefde zal blijven leven eens CS wordt geïnitieerd.

Hoofdstuk 4: Continue diepe sedatie en de hypothese van de 'natuurlijke dood'

Zoals al eerder vermeld, wordt CDS zeer frequent toegepast. Dit is vreemd aangezien de standaardvisie op sedatie is dat het een 'allerlaatste redmiddel' is. De vraag stelt zich dus wat de populariteit van CDS verklaart, en de hypothesis die ik naar voren schuif, heb ik de 'natuurlijke dood' hypothese genoegd. Deze stelt dat CDS zodanig populair is omdat het overlijden na sedatie kan worden gezien of voorgesteld als een 'natuurlijk' overlijden.

Het idee dat men een natuurlijke dood sterft na sedatie is zeer aanwezig in de literatuur, maar is amper bevraagd. Vaak is bovendien onduidelijk wat men met een 'natuurlijk overlijden' bedoelt, maar als we naar de literatuur kijken, zijn er een aantal elementen waardoor men CS kan associëren met een natuurlijke dood. Ten eerste sterft men zowel in een natuurlijke dood als in CS in een diepe slaap. Ten tweede gaat het in beide gevallen om een zachtjes wegglijden tot het overlijden. Ten derde wordt vaak beweerd dat men in CS, net zoals in een natuurlijk overlijden, enkel sterft aan de aandoening en niet aan een externe oorzaak. Hierdoor is er geen verlengen of verkorten van het leven. Als laatste zouden een overlijden na CS en de natuurlijke dood ook gemeen hebben dat de dood niet het resultaat is van menselijk handelen.

Echter, in CDS bevindt men zich niet in een diepe slaap, maar in een medisch geïnduceerde coma. Bovendien wordt het geleidelijke aspect van georkestreerd en is het dus verre van 'natuurlijk'. Het is ook maar zeer de vraag of men werkelijk sterft aan zijn aandoening in CS, aangezien er duidelijk wel menselijk handelen speelt. De gelijkenis tussen een overlijden na CS en een natuurlijk overlijden is dus louter *schijn*.

De vraag is waarom deze schijn wordt opgehouden, en wij argumenteren dat het vaak werkt als een soort 'coping' strategie. Het verdeelt de verantwoordelijkheid voor het

overlijden en het maakt het overlijden onvermijdelijk, waardoor men zijn eigen aandeel kan minimaliseren. We hebben begrip voor het feit dat artsen en verpleegkundigen voor zichzelf een aantal moeilijke beslissingen moeten kunnen verantwoorden, maar het mag niet leiden tot een situatie waarin CDS wordt voorgesteld als de enige goede manier om te sterven. Voor sommige patiënten, die bewust willen blijven tot het einde, is het geen goed alternatief.

Hoofdstuk 5: Is continue sedatie aan het levenseinde een moreel verkieslijk alternatief boven medisch geassisteerde zelfdoding

Zoals hierboven al geargumenteerd, roept CS enige controverse op. Een praktijk die nog meer controverse oproept is medisch geassisteerde zelfdoding (MGZ). Vaak worden CS en MGZ aan elkaar gekoppeld, bijvoorbeeld in een arrest van het Amerikaanse Supreme Court, waar een van de rechters opmerkte dat zij geen reden zag om MGZ te legaliseren aangezien continue sedatie steeds een mogelijkheid is. Dit lijkt de impliceren dat CS het moreel verkieslijke alternatief is voor MGZ, en we hebben dit het 'argument van morele verkieslijkheid' genoemd.

Dit argument komt vaak voor in de literatuur, maar kent een aantal varianten. Volgens de eerste variant van het argument is er geen juridische reden om MGZ te legaliseren aangezien er reeds een alternatief voorhanden is, namelijk CS, dat bovendien reeds legaal is. Echter, we argumenteren dat CS geen volwaardig alternatief is voor iedereen die MGZ wenst, aangezien beide praktijken om verschillende redenen en vaak door verschillende types personen gekozen worden.

Volgens een tweede variant is CS moreel verkieslijker omdat het geen gevaar inhoudt op een hellend vlak, iets wat bij MGZ wel het geval zou zijn. Echter, de data uit België, Nederland en Oregon wijzen niet op een hellend vlak bij MGZ. Bovendien is het niet duidelijk dat CS geen gevaar op een hellend vlak inhoudt.

Een derde variant stelt dat CS moreel verkieslijk is boven MGZ, omdat CS compatibel is met de rol van de arts als 'genezer', terwijl MGZ dat niet is. Echter, iemands bewustzijn permanent wegnemen om lijden te bestrijden is geen genezen, en als het dat wel zou zijn, dan zou MGZ ook onder 'genezen' vallen. Immers, CS bestrijdt geen symptomen, alleen de ervaring er van.

Volgens een laatste variant is CS moreel verkieslijk omdat het een compromis vormt tussen voor- en tegenstanders van MGZ, maar zoals hierboven beargumenteerd, beschouwen we dit niet als waardig compromis.

De conclusie is dat CS in sommige gevallen inderdaad moreel verkieslijk kan zijn boven MGZ, maar er is geen reden om te stellen dat dit *per definitie* zo zou zijn.

Hoofdstuk 6: Kan de doctrine van het dubbele effect een justificatie vormen voor CS?

Wanneer het gaat over de ethische justificaties van CS, wordt de doctrine van het dubbele effect het vaakst ingeroepen. Deze doctrine stelt dat er een verschil is tussen het intentioneel veroorzaken van een kwaad en het veroorzaken van een kwaad als neveneffect van een goede daad. Euthanasie, bijvoorbeeld, is niet toegelaten volgens DDE omdat men het leven doelbewust beëindigt. Wanneer men pijnmedicatie geeft waarvan men weet dat een levensverkorting mogelijk is, zegt de DDE dat dit toegelaten is, omdat men in dit geval niet bedoeling heeft om het leven te verkorten, maar eerder om de pijn weg te nemen.

Vele commentatoren zijn van mening dat deze doctrine ook van toepassing is op CS aangezien men in CS ook niet de intentie heeft om het leven te verkorten. Echter, de toepassing van DDE op CS wordt weinig in vraag gesteld. Ten eerste is het belangrijk om te verduidelijken dat er vele vormen van DDE zijn, maar dat bij het inroepen van dit principe in de literatuur, deze vormen weinig of niet onderscheiden worden.

Bovendien is de toepassing van DDE op CS, volgens ons, problematisch. Sommige auteurs beweren dat in CS de intentie is om pijn te bestrijden, terwijl het negatieve (maar onbedoelde) effect is dat het leven wordt verkort. Echter, deze commentatoren negeren dat er in sedatie sprake is van een tweede kwaad, namelijk het permanent beëindigen van iemand bewuste leven.

Sommige auteurs nemen daarom bewustzijn op als een onbedoeld kwaad in hun toepassing van DDE. Echter, hoe kan het verminderen van bewustzijn worden beschouwd als neveneffect van medicatie waarvan het primaire doel het doen dalen van bewustzijn is? Bovendien zou deze toepassing van DDE op CS alle gevallen veroordelen waarbij men gebruik maakt van bewustzijnsdaling om lijden te verminderen en net dat is waar CS om draait.

Het geheel wordt nog complexer wanneer we ook kijken naar sedatie die gecombineerd wordt met onthouding van vocht en voeding. Bovendien blijkt uiteindelijk dat men vaak niet eens DDE toepast in de justificatie van CS. Vaak verantwoordt men CS door de negatieve effecten af te wegen tegenover de voordelen ervan, maar dit is geen DDE redenering.

Hoofdstuk 7: Het klinische en ethische belang van het meten van bewustzijn

Iets dat in alle richtlijnen over sedatie terugkomt is het idee dat de praktijk proportioneel moet worden toegepast in verhouding tot de ernst van de symptomen. Dit is ook belangrijk vanuit een ethisch perspectief. Het bewustzijn is een belangrijk deel van wie wij zijn als persoon, dus het wegnemen ervan kan niet moreel neutraal zijn. Ethisch gezien lijkt het dus verkieslijk het bewustzijn slechts zoveel te verlagen als absoluut noodzakelijk.

Het bewustzijn is een complex gegeven. Vanuit de anesthesie literatuur weten we bijvoorbeeld, dat sommige patiënten wakker zijn tijdens een operatie, maar toch alle tekenen vertonen van rustig verdoofd te zijn. Of een patiënt rustig lijkt is dus geen ideaal criterium voor de diepte van sedatie en al zeker niet bij terminaal zieke patiënten in slechte fysieke conditie.

Echter, hoewel men proportionaliteit belangrijk vindt, wordt de effectieve diepte van sedatie bij individuele patiënten amper gemeten. Desalniettemin zijn er verschillende technieken. De meest gebruikte is misschien wel de gewone klinische observatie. Zoals hierboven al aangegeven is dit problematisch aangezien sommige patiënten er rustig kunnen uitzien, terwijl ze nog bij bewustzijn zijn.

Een andere techniek is het gebruik van sedatie schalen. Ondanks enkele voordelen, gaan deze ook verder op klinische observatie. Bovendien vereisen ze dat de patiënt (licht tot hevig) wordt geprikkeld (bv. porren of schudden), waardoor de schalen enigszins invasief zijn.

Bij andere technieken kan de hersenactiviteit rechtstreeks worden gemeten. Hoewel een EEG zelf te complex is, zijn er verschillende toestellen die de EEG reduceren tot een simpele waarde die de diepte van sedatie weergeeft. Deze techniek is weinig invasief (ze vereist slechts het aanbrengen een patch op het voorhoofd van de patiënt) en is veelbelovend qua resultaten.

De conclusie is dat er meer zou moeten gemeten worden indien men wil volhouden dat proportionaliteit een cruciale rol speelt bij sedatie en dat de klassieke technieken niet noodzakelijk de beste zijn

Hoofdstuk 8: Factoren die het gebruik van CS door artsen en verpleegkundigen in België vergemakkelijken of bemoeilijken

Na de besprekingen van de verschillende manieren waarop CS wordt voorgesteld in de internationale literatuur, is dit hoofdstuk een rapportering van vier focusgroepen die gehouden werden in april 2010 en waarin we artsen en verpleegkundigen vroegen naar hun ervaringen met CS. De vragen die tijdens de focusgroepen werden gesteld, werden deels beïnvloed door de bevindingen in de vorige hoofdstukken. De specifieke onderzoeksvraag was: 'welke factoren maken in een bepaald geval het gebruik van sedatie meer of minder waarschijnlijk volgens artsen en verpleegkundigen in België?'

We deden vier focusgroepen waarvan twee met enkel artsen (n=4 & n=4) en twee met enkel verpleegkundigen (n=4 & n=9). Voor de rekrutering hebben we contact opgenomen met persoonlijke onderzoekscontacten en hebben we een uitnodiging gestuurd naar een verschillende artsen en verpleegkundigen via de Orde van Geneesheren en Domus Medica. Als inclusiecriterium stelden we dat elke deelnemer minstens eenmaal in zijn carrière moest betrokken zijn geweest bij een geval van continue sedatie. De focusgroepen werden elektronisch opgenomen, getranscribeerd en later door twee onderzoekers afzonderlijk gecodeerd. In de laatste fase werd een consensus bereikt over de finale codering.

De participanten brachten een aantal belangrijke factoren aan die hun gebruik van CS kunnen beïnvloeden. De eerste factor was de fysieke staat van de patiënt. Voor veel artsen en verpleegkundigen kon CS enkel worden toegepast bij patiënten in slechte fysieke staat met een korte levensverwachting.

Ten tweede gaven de artsen en verpleegkundigen ook aan dat een expliciet verzoek van een patiënt de kans op sedatie aanzienlijk verhoogt. Spijtig genoeg was dat, volgens de participanten, niet vaak het geval omdat vele patiënten de praktijk niet kennen en de arts vaak CS niet als eerste wil aanbrengen. Bovendien wordt de communicatie vaak bemoeilijkt door onrealistische verwachtingen van de patiënt of zijn/haar familie.

Twee andere factoren die het gebruik van sedatie beïnvloeden zijn de aan- of afwezigheid van richtlijnen en de algemene attitude van de arts of verpleegkundige.
Een laatste relevante factor is de mogelijkheid tot alternatieven. Vele participanten vonden CS enkel mogelijk wanneer het absoluut de laatste techniek is om het lijden weg te nemen.

De conclusie is dat veel artsen en verpleegkundigen een goed beeld hadden op de situatie waarin zij het gebruik van CS als makkelijk zouden ervaren: bij een competente

patiënt die om CS verzoekt en in zijn laatste dagen is en extreem lijdt. Tezelfdertijd werd door vele deelnemers gesteld dat deze 'ideale' situatie zich zeer zelden voordoet.

Hoofdstuk 9: Gelijkenissen en verschillen tussen CS en euthanasie: de attitudes en ervaringen van professionele zorgverleners

Ook dit hoofdstuk is een rapportering van vier focusgroepen die we deden in april 2010. De gevolgde methodologie staat hierboven beschreven. De specifieke onderzoeksvraag voor dit hoofdstuk was hoe professionele zorgverleners het verschil tussen CS en euthanasie ervaren en wat hun attitudes hieromtrent zijn.

Voor vele deelnemers waren continue sedatie en euthanasie uitermate verschillend. Ten eerste rapporteerden ze dat er wat betreft sedatie minder vaak een expliciete vraag komt, iets wat uiteraard wel vaak voorkomt bij euthanasie. Bij sedatie begint het veelal met een algemene vraag of een algemeen verzoek om 'iets te doen', wat dan later uitgekristalliseerd wordt. In een communicatieproces ontwikkelen veel patiënten een voorkeur voor CS, dan wel voor euthanasie.

De deelnemers rapporteerden ook een verschil in de manier waarop de beslissing wordt gemaakt. Enkele verpleegkundigen waren van oordeel dat in CS het vaker de arts is die op zichzelf beslist, waardoor verpleegkundigen minder vaak worden betrokken bij de beslissing tot sedatie dan bij euthanasie.

Een ander essentieel verschil volgens de deelnemers is de intentie waarmee de praktijk wordt uitgevoerd. Bij euthanasie is het de bedoeling het leven te verkorten of te beëindigen, maar in sedatie is vaak het comfort van de patiënt de enige intentie (zie de bespreking van dubbel effect hierboven).

Hoewel vele deelnemers CS en euthanasie als verschillend beschouwden, reflecteerden ze ook over situaties waarin het onderscheid tussen beiden minder helder zou zijn. Een goed voorbeeld, volgens sommige participanten, is wanneer de medicatie in CS disproportioneel wordt opgedreven. Wanneer dit gebeurt dan kan een geval van CS verglijden naar een geval van euthanasie. Een ander voorbeeld van een geval waarin de grens tussen CS en euthanasie dunner wordt, is wanneer CS wordt geïnitieerd bij patiënten met een langere levensverwachting. Immers, in dit geval is de kans op levensverkorting aanzienlijk.

Deze studie toont de complexiteit aan van continue sedatie aan het levenseinde. Hoewel het voor vele deelnemers duidelijk was dat CS verschilde van euthanasie, konden de

meeste deelnemers gevallen voor de geest halen waar het onderscheid minder duidelijk was.

Conclusies

Deze dissertatie geeft een inzicht in de manieren waarop de praktijk van continue sedatie wordt voorgesteld in de internationale literatuur. De vaakst voorkomende voorstellingen van CS werden geanalyseerd naar hun ethische validiteit. De conclusie is dat sedatie vaak wordt beschouwd als een onproblematische of zelfs verkieslijke praktijk, maar dat vele van deze perspectieven ethisch gezien onhoudbaar zijn. Bovendien delen ze een aantal gelijkaardige problemen

Dubbelzinnig en misleidend taalgebruik

Iets wat vele van de standaardvoorstellingen van sedatie gemeen hebben is dat ze zich vaak beroepen op dubbelzinnig taalgebruik. Ze maken vaak gebruik van concepten die zowel een descriptieve als een normatieve betekenis hebben, waarbij het niet steeds duidelijk is in welke betekenis een bepaald concept wordt gebruikt. Een goed voorbeeld is het descriptieve concept 'natuurlijk overlijden'. Echter, dit concept wordt ook vaak gebruikt op een normatieve manier om aan te duiden dat we een bepaald overlijden als 'goed' dienen te beschouwen. Een ander voorbeeld is 'normaal medisch handelen', iets wat een louter beschrijvend en juridisch concept is, maar door vele auteurs buiten die context gebruikt wordt, wat verwarring creëert.

Bovendien is veel van de gebruikte taal niet enkel dubbelzinnig, ze is vaak ook misleidend. In deze dissertatie heb ik geprobeerd aan te tonen waarom het, volgens mij, incorrect is om een overlijden na CS te beschouwen als een 'natuurlijk overlijden', waarom CS geen moreel verkieslijk alternatief is, waarom DDE niet van toepassing is op sedatie, en waarom men alleen kan spreken van 'proportionele sedatie' als men ook effectief de diepte van de sedatie meet.

Empirisch onderzoek

Daarnaast heb ik in deze dissertatie ook empirisch onderzoek gerapporteerd, namelijk een focusgroep studie met artsen en verpleegkundigen. De resultaten van deze studie bevestigen en ondersteunen, naar mijn mening, de ethische analyses van dit werk. Vele

deelnemers van de focusgroepen maakten gebruik van de standaardvoorstellingen van sedatie zoals besproken in deze dissertatie. Bovendien bevestigt de focusgroepenstudie ook dat vele van deze voorstellingen problematisch zijn. Zowel in hoofdstuk 8 als in hoofdstuk 9 is het duidelijk dat de deelnemers rapporteerden dat sedatie verre van altijd ideaal is. Vaak is er geen verzoek van de patiënt, soms kan sedatie disproportioneel worden opgedreven of kan ze te vroeg worden opgestart. De conclusie van het empirische deel is dus gelijk aan die van het theoretische deel: er is nood aan een eerlijk en open debat rond continue sedatie aan het levenseinde omdat ondanks het feit dat vele gevallen van sedatie onproblematisch zijn, er toch gevallen zijn waarbij ethische vraagtekens geplaatst dienen te worden.

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Curriculum vitae Kasper Raus

Kasper Raus was born on 27 October 1986 in Mol, Belgium. After having finished his high school in Mol, he moved on to study philosophy in Ghent, and graduated as Master of Science in Philosophy in 2008.

In March 2009, he started working on a PhD project on ethical and empirical aspects of continuous sedation at the end of life, supervised by Prof. dr. Sigrid Sterckx, and co-supervised by Prof. dr. Freddy Mortier and Prof. dr. Luc Deliens. He is a member of the Bioethics Institute Ghent (BIG) of Ghent University and the End-of-Life Care Research Group Ghent University & Vrije Universiteit Brussel.

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