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1 Introduction

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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 (fictionalised) 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 conceptualised 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.

In the context of 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 caregivers and loved ones. 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 book 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.

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

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

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about their opinions regarding continuous sedation. Ninety-eight per cent 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 2009b).

However, continuous sedation until death has recently become subject to criticism, for various reasons. One reason has to do with the increase in its frequency: dying after having been continuously sedated for some time is fast becoming one of the standard ways of dying. This book represents an attempt to understand why this is happening and asks whether it is a desirable evolution.

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 per cent 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 per cent 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. (2000) studied four palliative care programmes (in Israel, Durban, Cape Town and Madrid), showing that more than 90 per cent of all palliative care patients in the inpatient setting required symptom control or management. 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

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[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.

free from pain is nothing less than a fundamental right. As bioethicist Margaret Somerville 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)

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, it is not only the ethical acceptability of continuous sedation at the end of life that is under discussion, so too is its legality (see, for example, Gevers 2004 and Chapter 8 in this volume by Delbeke).

In the absence of a single framework or procedure, there is no widely agreed 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. Many of the debates are scattered across the literature of several different disciplines. Thus, for this volume, we have endeavoured to bring together experts from the various disciplines in which continuous sedation is debated. Before outlining the different chapters, we provide some comments on topics in the 'sedation debates' that are so recurrent that they merit specific attention in this introductory chapter.

3. Defining sedation at the end of life

The starting point for many of the chapters in this book is that 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 2005b; 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. 2001c; 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. 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; and van Delden, Chapter 13 this volume), 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 and 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 towards 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 (this volume, Chapter 6) 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

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coping on the part of healthcare personnel. This issue is not addressed in this volume, but it deserves mentioning here.

4. Artificial 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, Chapter 13 in this volume, and Holm, Chapter 14) 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

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[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 seventeenth 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).

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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 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 Chapter 13 in this volume). 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, Chapter 14 in this volume) point out that the concept of 'futility' is often misused in this context.

Sykes (Chapter 5, this volume), 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 taken 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

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> 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: 142–3, references omitted)

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

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. Indeed, it is mentioned in most of the chapters in this volume. For DDE (in its most common interpretation, viz. the natural law interpretation, as explained in Chapter 11 by Raus, Sterckx and Mortier) to be an adequate justification for continuous sedation, some conditions need to 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 in this volume as to whether this indeed forms a problematic aspect of continuous sedation at the end of life and, if so, whether and how it