CHAPTER XIV

Palliative Sedation

An Exploration from a Christian Ethical Point of View

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Introduction

In this chapter we will explore some ethical questions concerning palliative sedation from a Dutch and Christian angle. "Dutch and Christian" is not as easy as it may sound. Until the 1960s, it was safe to describe the Netherlands as a Christian country. Historically, we could point to the roles played by churches and believers in establishing and running health care institutions. But in recent decades the relationship of the Dutch to their religious origins has become more ambiguous. Despite protests from conservative Christian churches, organizations, and politicians, abortion, birth control, assisted reproduction (including the use of donated gametes), and euthanasia¹ were accepted and made legally possible. Patient (or client) autonomy became a major competitor to the allegedly paternalistic approach of Christianity. The former connections between Christianity and medicine have not dissolved, but a self-evident identity between the two can no longer be assumed either. The further the emancipation of medical ethics from Christian ethics progresses, the more urgent it becomes to ask if a Christian view (the Christian view does not exist) differs from a view prop-

¹ Since the 1980s, the term "euthanasia" in the Netherlands has always implied, by definition, a life-terminating intervention by a physician as well as the request from the patient. Both "active euthanasia" and "voluntary euthanasia" are pleonasms. "Non-voluntary euthanasia" is now referred to as "life termination without request"; "passive euthanasia" is referred to as "withdrawing treatment."

agated by, for example, the Dutch government or the Royal Dutch Medical Association (hereafter RDMA (Dutch: KNMG)).

Unlike abortion or gay marriage, however, palliative sedation does not create similar sharp disagreements beforehand between Christians and others. Most doctors, irrespective of their religion or worldview, are convinced that the number of euthanasia cases should be as limited as possible. Palliative sedation has been welcomed by many as an alternative to euthanasia provided that the conditions of serious suffering, refractory symptoms, a patient's consent, and the absence of the intention to shorten the patient's life apply. There seems to be a relatively broad, and in my eyes beneficial, societal consensus on the moral acceptability of palliative sedation. But even so, important questions remain. In what follows I will identify the most pressing ones.

Palliative Sedation Only Hours or Days before an Expected Natural Death?

Palliative sedation means the administration of drugs to keep the patient in deep sedation or coma until death without artificial nutrition or hydration (Rietjens et al 2004: 179). The RDMA distinguishes between intermittent sedation and continuous sedation until death. The latter is also known as terminal sedation. In the Netherlands, it is estimated that in 2010 12.5% of all deaths were preceded by palliative sedation, a considerable increase in comparison to an estimated 8.2% of all deaths in 2005 (Van der Heide et al 2012: 107). The majority of patients receiving palliative sedation suffer from cancer in a terminal phase. The growing incidence of palliative sedation can be seen as a consequence of the development of medical technology that can be operated both institutionally and at home without continuous attendance of a physician or nurse. A more intriguing explanation, applying specifically to the Netherlands, may be found in a preference on the side of many doctors, patients, and others to avoid euthanasia.

Technically, palliative sedation is a form of medical treatment. As Lieverse, Hildering, and Klaasse-Carpentier (2009) convincingly argue, however, it is an uncommon form of nor-

mal medical treatment. After all, a patient *and* his² autonomy are put to sleep for the rest of his life, and the dying process may be shortened. Possible criteria we will consider here are: (1) the suffering must be intolerable; (2) the symptoms should be refractory, i.e. they cannot be sufficiently relieved by using less radical palliation—painkillers, tranquillizers, anti-emetics, etc.; (3) the patient must consent to being sedated; (4) a natural death is expected within days or weeks; (5) the palliative sedation should not shorten his life.

According to the RDMA guidelines, no nutrition and hydration are administered in cases of palliative sedation.³ One reason for this policy is that hydration may deteriorate a patient's condition by, for example, contributing to his ascites or by increasing the quantity of fluid in the lungs. When death is expected within hours or days, withholding hydration will hardly hasten a patient's death, nor will it do much good. And, since *any* dying patient at some point stops eating and drinking, why force hydration on patients in a state of sedation when they are dying?

The issue becomes more complicated when a patient has longer than a week to live: without hydration, *any* sedated person, terminally ill or not, will die within days or weeks. In order to preclude the possibility that palliative sedation causes a patient's death, the RDMA has ruled that palliative sedation may only be given when a natural death is expected within 1-2 weeks. But how accurate can the assessment of a patient's life expectancy be? An experienced doctor may be reasonably certain in saying that a patient will die within hours or a day or two: the patient's breathing changes, his skin becomes pale. He may also be reasonably certain in predicting that natural death can roughly be expected to occur within weeks or months from

² The words "he" or "his" are used inclusively in this chapter.

³ Officially, the guideline speaks of "withholding nutrition and hydration." In this chapter I will refer to hydration, not only for the sake of brevity but also because one of the most problematic aspects of palliative sedation—its life-shortening effect—seems to be caused mainly by the dehydration of a patient.

now. But it is hard to claim convincingly that natural death will occur within, let us say, five or eight days. In the end, the patient may die much sooner of much slower.

So what about the RDMA's requirement that a natural death be expected within one or two weeks? That a patient in a terminal stage of a disease will die is certain. But no prediction is infallible. Some patients outlive the most "optimistic" predictions of their doctors; others die much sooner. Even if the RDMA's guidelines are followed, it cannot be ruled out that a decision to start palliative sedation will in effect shorten a patient's life because the patient would have lived much longer without being sedated.

This brings us to the following question: If the principal objective is palliation, why restrict this kind of treatment to patients with a life expectancy of less than 1-2 weeks? What about patients with a longer life expectancy who suffer from the same refractory symptoms—anxiety, pain, nausea, fatigue, dyspnea? According to the RDMA, they do not qualify for palliative sedation. From my own observations,⁴ it becomes clear that a doctor's refusal to administer palliative sedation sometimes leaves patients no other option than a euthanasia request, despite a *prima facie* aversion for euthanasia.

Is There a Moral Obligation to "Feed the Hungry"?

Since the Christian thinker Thomas Aquinas (1225-1274), the principle of double effect (PDE) has been pivotal for making difficult decisions regarding life and death. According to Aquinas, many actions have two kinds of effects: (1) a foreseen and *intended* effect, such as pain relief as the effect of administering painkillers, and (2) a foreseen but *unintended* effect, such as an earlier death as a consequence of painkillers. The PDE holds

⁴ Unpublished; during my participation in a Regional Review Committee for Euthanasia, I reviewed about 3,100 euthanasia cases reported by physicians in the years 2005-2013. Observations from these materials provide important indications but do not stand the test of statistics. Quotations from the reports have been changed to protect the privacy of those involved.

that some things may be permissible if they are the unintended effect of an action performed with the intent to bring about something else. Most Christian thinkers consider the intentional killing of an innocent human being (even at his request) to be wrong. Yet if a death is the foreseen but unintended result of another action and this death is not in itself a means, the PDE holds that such a death may sometimes be justified, provided that everything has been done to prevent this effect (Wogaman 1994: 92; Biggar 2003: 59ff.). Applied to the context of palliative medicine, the PDE means that we may be excused if we have caused the death of a suffering person provided that this death is the unintended result of the necessary and proportional administration of painkillers and/or sedatives and provided that this death could not have been avoided. Euthanasia cannot be justified on the basis of the principle because death is the intended effect here.

With the principle of double effect in mind, we may ask some questions about the RDMA's guideline, which seems to imply the following logic on the criterion of life expectancy:

- (1) palliative sedation implies withholding hydration;
- (2) without hydration, people will die within 1-2 weeks;
- (3) palliative sedation should not be the cause of a patient's death;
- (4) therefore, patients with longer than 1-2 weeks to live do not qualify for palliative sedation.

The first question that comes to mind is: Why would palliative sedation necessarily imply withholding hydration? We indicated some of the reasons above: hydration can deteriorate a patient's condition, and *any* dying patient will at some point stop eating and drinking. But what if these reasons do not apply, such as when a patient has longer than 1-2 weeks left?

This equation of "artificial hydration" and "prolonging life" in the case of palliative sedation will not be convincing to all. We can reverse the logic and argue that the real issue is not the alleged *life-prolonging effect of artificial hydration* but the *life-shortening effect of palliative sedation*. In line with the PDE, we can argue that the life-shortening effect of palliative sedation is acceptable only if measures have been taken to prevent an ear-

lier death from occurring. Administering hydration would meet this requirement.

Is there a moral obligation to administering some hydration then? A distinction frequently made in medical and nursing practice is the distinction between (medical) treatment and care (Teeuw 2003). The duty to provide care is, all other things being equal, harder than the obligation to give treatment. A doctor's decision to refrain from surgery on a dying patient, for example, is less problematic than a decision to refrain from feeding that same patient. Correspondingly, a patient's claim to care is more difficult than his claim to treatment. In the Christian tradition, the obligation to "feed the hungry" has always had high status. The RDMA's decision to restrict palliative sedation to patients with only 1-2 weeks to live may be understood in the light of this "preference for life": no life-shortening effect of palliative sedation! But instead of limiting the option of palliative sedation to patients shorter than 1-2 weeks to live, why not discuss the option that only patients with a life expectancy of hours or days will not be administered hydration, and why not consider the option that all other forms of palliative sedation should include the possibility of administering hydration? Why not give access to palliative sedation to all patients with refractory symptoms, irrespective of their life expectancy? Such a less rigid approach would be congruent with practices found in other countries. In Italy, for example, 65% of the patients receiving palliative sedation do receive artificial hydration, compared to 36% in Denmark and the Netherlands (Simon et al. 2007). Why not discuss the risks, benefits, and goals of fluids before initiating terminal sedation instead of rejecting such a discussion beforehand?

But the RDMA may be more "right" than suggested here. A Dutch survey indicated that about two thirds of the physicians who administer palliative sedation not only intend to alleviate the suffering but also to hasten death. Moreover, a patient has the right to refuse treatment and care. If a patient suffers from a terminal disease and wishes to be placed in an artificial coma, this probably indicates that that patient does not want to be kept alive by artificial means. Many of those who qualify for palliative sedation will use their right to refuse food and drink—a right based on considerations of patient autonomy and bod-

ily integrity. There can be no obligation on the part of the patient to accept artificial hydration.

So if palliative sedation is made accessible to all patients with refractory symptoms, irrespective of their life expectancy, some doctors, along with their patients, may be tempted to use palliative sedation instead of euthanasia. In light of this, the 1-2 weeks of life expectancy in the RDMA guideline can be better understood. Still, we can consider another option: if a patient has longer than a week or so to live, why not issue a second guideline in which sedation is offered intermittently—and only in combination with the administration of hydration? Cooney suggests so-called "respite" sedation of a predetermined duration, followed by a lightening of unconsciousness to assess response (Cooney 2000). Patients have a right to refuse artificial hydration, but a doctor may, in turn, refuse to administer continuous sedation to such a patient. If a patient nevertheless refuses hydration during sedation in a non-terminal state, there are good reasons to consider this analogous to a euthanasia request. The patient not only wants relief for the suffering; he also wants a termination of his life. We will return to this below.

Other Religious Questions

Palliative Sedation as Unnatural?

In the Christian tradition, Roman Catholics especially have insisted that human life be lived as much as possible in accordance with the "natural order of things" or within the "creation order." Thomas Aquinas stands out as the most influential representative of religious natural law thinking. Protestant Christians have traditionally been more skeptical about the normativity of "nature" or "creation" for human actions. Within a religion that considers sickness and death a consequence of human sinfulness, it is indeed hard to argue for a "natural way to die." Still, influential voices within the Christian tradition argue that both life and death should be as "natural" as possible. Palliative sedation takes an interesting position here, since it is found somewhere between the "unnatural" death of euthanasia and the "natural" death of dying in consciousness and distress. Christians who strongly oppose euthanasia tend to be strongly in favor of palliative sedation.

Palliative Sedation as the End of Human Autonomy?

In health care in Western countries, patient autonomy has become one of the most important moral principles, if not the most important (Beauchamp and Childress 2001). Important contributors to this stress on autonomy were the Reformation (Lutheran) theologian Martin Luther (1483-1546) and the Enlightenment philosopher Immanuel Kant (1724-1804) who interpreted human self-determination in terms of personal responsibility. Given the fact that modernism and postmodernism reinterpret autonomy in terms of individual liberties, Christian churches have developed an increasingly paradoxical attitude: following Kant, they welcome human autonomy; but, also following Kant, this autonomy does not consider the human will to be the source of our morality. Autonomy is not "doing as we please" but rather "directing our wills to affirming a moral law which transcends our subjectivity." Franz Böckle describes this ambiguity in terms of "theonomous autonomy" (Böckle 1972: 233). Likewise, the Dutch theologian Harry Kuitert states that "autonomy" is intended to free an agent from undue pressure from his fellow human beings and not to liberate him from obligations issued by God (Kuitert 1993: 73).

If autonomy (or the more "traditional" concept of responsibility) is seen as a human characteristic and a human duty, an obvious problem of the practice of palliative sedation is that it can be interpreted as "putting an end to human autonomy." Kant's main argument against suicide is that through it a person abandons his autonomy. (John Stuart Mill compared suicide to a person's decision to sell himself into slavery.) A reconstructive interpretation of the Christian tradition and Kant in the context of sedation may imply the view that palliative sedation should be rejected *prima facie* for exactly the same reason: through it the individual abandons his capacity to act autonomously or responsibly. This objection pertains all the more to cases of sedation in which no hydration is administered and in which the sedation will go on until death. In the case of intermittent sedation, a person abandons his autonomy only temporarily.

Palliative Sedation as an Answer to Experiences of Meaninglessness?

The most common reason for palliative sedation is to relieve symptoms of physical suffering: dyspnea, pain, incontinence, nausea, and fatigue. Part of the suffering is of a psychological, psychosocial, or existential nature: meaningless waiting, the absence of social contacts, the loss of freedom, being dependent on others for one's daily needs. Christianity, like most religions, searches for meaning in situations of suffering (cf. Boer and Groenewoud 2011: 29ff.). It may even be said that religions as such are attempts to discover or create meaning in seemingly meaningless circumstances. This meaning can contribute to alleviating suffering: religion in itself may function as a form of "palliative care." Suffering is not seen as intrinsically good; it may even be seen as intrinsically bad. Nevertheless, it may be used instrumentally for the realization of intrinsic goods. First, the meaning of suffering is sometimes found in its contribution to establishing loving, caring, faithful, and trusting personal relations. Second, the dying person himself may be able to discover or create meaning in the final stretch of his life. The ars moriendi, the art of dying well, is often considered a means to obtaining moral virtuousness: by praying, by detaching oneself from the life one has lived, by repenting for one's failures, and by reconciling oneself with one's adversaries, a human being may become more virtuous, more patient, more courageous, more hopeful (cf. Verhey 2011). From a Christian point of view—an interesting aspect in an Islamic-Christian dialogue an example may be found in the conviction that God, incarnated in a human being, suffered an undeserved death without becoming bitter, cynical, or resentful.

Suffering consists in part in the awareness that most of the things that make life worth living—happiness, health, prosperity, growth, creativeness, communication—are losing ground. Traditionally, religions have developed practices of consolation in which this loss of human goods was relativized. They acknowledged the fact that humans may lose their health, independence, and well-being, but this does not, in the view of these religions, in any way threaten their value or humanity. In contrast to the somewhat hedonistic *adagium*, "life should be enjoyed," that sometimes pops up in contemporary Western

culture, the Christian *adagium* may better be stated as "life should be lived"—including in the harder and hardest of times.⁵ Frequent reference is also made to the Christian hope of a final "restoration of all things." The prospect of life after death motivates people not to give up hope. Despite some differences between Islam and Christianity on suffering, they share the conviction that God will, in the end, grant the faithful a life that may be all the more rich and rewarding, depending on the degree of patience and faith that one has learned during one's earthly life. All these views do not render palliative sedation wrong or redundant as a category of acts. In some cases, they may even help to *motivate* the choice for palliative sedation.

Is Palliative Sedation Always the Proportional Answer to Suffering?

We return now to a more medical perspective. Not all palliative sedations are the same. The American Hospice and Palliative Nurses Association defines palliative sedation as "the monitored use of medications intended to induce *varying degrees of unconsciousness*, but not death, for relief of refractory and unendurable symptoms in imminently dying patients" (HPNA 2003, italics mine). Generally speaking, the sedation should not be deeper than necessary to keep the patient unconscious: "First stage anesthesia," not deep sedation, is the goal. Higher dosages may increase the chance that a patient's death is hastened.

Before referring to the common answer that a patient in an artificial coma cannot experience suffering, we need to address the question if the sedation is always sufficiently deep. Depending on the depth of the coma and on the effectiveness of the sedatives given, sedated persons may display expressions of discomfort, such as rattling and irregular breathing (Cheyne-Stokes respiration), and groaning. The Hospice and Palliative Care Federation of Massachusetts suggests that heavy snoring and abrupt onset of apnea may be caused by too high a dosage of sedatives (HPCF/MA 2004). In other cases, the dosage of sed-

⁵ It is said that Dutch writer Harry Mulisch, who died in October 2010 from cancer, rejected the option of euthanasia because he wanted to feel what it is like not only to live but also to die.

atives may have to be increased. In one of the euthanasia reports a physician writes:

Patient was sedated but continued to express pain: groaning, grimacing, gesturing, mumbling, "help me." The relatives insisted that I would perform the euthanasia the patient had requested, and that is what I did.⁶

Another doctor writes:

Palliative sedation would be an option but patient has traumatic memories of her husband dying in a state of palliative sedation: staring at the ceiling he was waiting for his death for days.

And a third doctor states:

Patient is afraid that if I give her palliative sedation, she will still be suffering from her pain, but without the possibility of expressing herself. For this reason, she requests euthanasia.

From these and other reports in the euthanasia review procedure, it becomes clear that some terminal patients reject palliative sedation out of fear that it will not lead to the intended effect. A properly conducted sedation implies a coma that is deep enough to preclude experiences of suffering in a patient. On the other hand, the dosage should not exceed the patient's need for palliation. When sedation is properly conducted, it may be proper for a physician to explain to the bystanders that irregular breathing or rattling may be unpleasant for bystanders to witness, but the patient himself is no longer suffering.

The Netherlands was the first country in which euthanasia and physician-assisted suicide (PAS) were made legally possible (Boer 2007: 529-30). For some years, palliative sedation was heralded by some as *the* alternative to euthanasia: a natural death that spares all the involved parties the moral and legal hassles connected to euthanasia. If administered in accordance with accepted medical standards, the chances that palliative se-

⁶ This and the following citations are from the reports mentioned above. See note 4 above.

dation will shorten the patient's life are small: it is *not* "slow euthanasia." The next question, especially in a Dutch context, is: If palliative sedation takes away all the patient's suffering, why would euthanasia be even necessary?

A euthanasia case that was reported in 2006 to a review committee may serve to illustrate the moral complexity of this question. The case involves a physician who was to perform euthanasia on a terminally ill cancer patient. All the criteria set by Dutch law were met. The evening before the agreed date, the patient called the doctor in a state of distress. He insisted that euthanasia be performed right away. Since the physician did not yet have access to the lethal drug until the next morning, she administered a medication that induced a coma. The next morning she returned and, without waking the patient, performed the euthanasia as agreed. The review committee decided to report the case to the prosecutor. It based its verdict on a report written for the RDMA that suggests that a patient in a coma cannot experience unbearable suffering (Legemaate 2005: 40). In the view of the committee, the physician should either have awakened the patient to ask him or should not have proceeded.

The verdict discloses a pivotal and ever recurring issue in almost any euthanasia discussion: if a patient can be made comfortable with the help of advanced palliative techniques, including terminal sedation, what justification is there left to take the most radical measure and terminate both the suffering and the life of the patient? In a technical sense, the committee's verdict applies to most euthanasia cases in the Netherlands. Following RDMA guidelines, most physicians induce a coma (usually by using sodium thiopental) before the actual life termination takes place (usually through pancuronium bromide, a neuromuscular muscle relaxant). In the minutes between the administration of the two drugs, the patient is in a coma and seems to be free from suffering. Why would it be wrong to administer the pancuronium to a patient who has been in a coma for about twelve hours and right to do the same when the patient has been in a coma for three minutes?

This question, of course, cannot be discussed here. At the center of the discussion lies the question whether the primary goal of palliative care (including euthanasia and palliative seda-

tion) should be to alleviate a patient's suffering, to alleviate a patient's suffering *in a way acceptable to him*, or to fulfill a patient's autonomous wish. Many patients who are convinced that palliative sedation will end their suffering still opt for the much more radical option of euthanasia. Not only do they reject the prospect of suffering, but they also reject the prospect of existing unconsciously. In the terminology of the British philosopher Richard Hare, such a wish can be called a "now for then" preference (Hare 1981: 101). It remains to be seen if such wishes are irrelevant from a Christian point of view. But that the wish not to exist anymore carries a heavier burden of proof than the wish not to suffer can hardly be denied.

Concluding Remarks

In this chapter I have explored some questions with regard to palliative sedation from a Christian and Dutch perspective. I share the RDMA's contention that palliative sedation is a good option as long as death is not the underlying intention. Moreover, I share the view that palliative sedation should only be administered in case of refractory symptoms. It also seems safe to assume that, for Christian and secular (medical, professional) positions alike, palliative sedation is preferable to the more "unnatural" option of euthanasia or physician-assisted suicide.

There are also some concerns on my part. First, Dutch medical practice may be criticized for the fact that palliative sedation is not accompanied by the administration of hydration. As a result, patients who are not in a terminal stage of their illness are excluded from receiving sedation and some patients may even be forced to make a euthanasia request because they do not fill the criterion of terminality. The alternative would be to offer intermittent sedation to patients who are not in a terminal stage and to continue administering hydration during the sedation or between periods of sedation.

A second concern is based on a Christian and Kantian understanding of human autonomy: just as suicide is rejected because it puts an end to our capacity to be autonomous and responsible agents, palliative sedation may be considered problematic. Offering intermittent sedation would help to ease this moral tension: human agency would not be altogether abandoned. A third concern is that palliative sedation may some-

times be an inadequate *medical* answer to questions regarding *meaninglessness*. Neither concern is conclusive: notwithstanding both arguments, palliative sedation may in many situations still be the best alternative.

A fourth concern has a more medical character: sometimes the sedation is not deep enough, and the patient still experiences considerable suffering. In other cases, sedation may be deeper than necessary to ease the refractory symptoms. This leads to a final concern: it can clearly be rational and moral to wish to not suffer. But when the symptoms can be relieved without using sedation, can it still be rational to have a wish to be not conscient?

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