

**Special Article**

# Palliative Sedation Versus Euthanasia: An Ethical Assessment

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**Abstract**

*The aim of this article was to review the ethical debate concerning palliative sedation. Although recent guidelines articulate the differences between palliative sedation and euthanasia, the ethical controversies remain. The dominant view is that euthanasia and palliative sedation are morally distinct practices. However, ambiguous moral experiences and considerable practice variation call this view into question. When heterogeneous sedative practices are all labeled as palliative sedation, there is the risk that palliative sedation is expanded to include practices that are actually intended to bring about the patients' death. This troublesome expansion is fostered by an expansive use of the concept of intention such that this decisive ethical concept is no longer restricted to signify the aim in guiding the action. In this article, it is argued that intention should be used in a restricted way. The significance of intention is related to other ethical parameters to demarcate the practice of palliative sedation: terminality, refractory symptoms, proportionality, and separation from other end-of-life decisions. These additional parameters, although not without ethical and practical problems, together formulate a framework to ethically distinguish a more narrowly defined practice of palliative sedation from practices that are tantamount to euthanasia. Finally, the article raises the question as to what impact palliative sedation might have on the practice of palliative care itself. The increasing interest in palliative sedation may reemphasize characteristics of health care that initially encouraged the emergence of palliative care in the first place: the focus on therapy rather than care, the physical dimension rather than the whole person, the individual rather than the community, and the primacy of intervention rather than receptiveness and presence. J Pain Symptom Manage 2014;47:123–136. © 2014 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

**Key Words**

*End-of-life care, ethics, euthanasia, hospice philosophy, palliative care, palliative sedation, physician-assisted dying, terminal sedation*

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**Introduction**

The concept of “terminal sedation” was first introduced in the palliative care literature by Enck<sup>1</sup> in 1991 to describe the practice of drug-induced sedation for symptoms that are difficult to control. Since then, sedation practices for patients who are terminally ill or in the final stages of dying have rapidly

expanded. At the same time, there has been an extensive and growing debate about the ethical assessment of these practices. Almost from the start, the practices were considered controversial. Critics claimed that it was “slow euthanasia” or mercy killing in disguise.<sup>2–4</sup> They argued that the adjective “terminal” was not simply an indicator of time, reflecting the final phase of a patient’s life when such sedation was typically administered; instead, it revealed the real purpose of the intervention, that is, to terminate the patient’s life. Because the concept of terminal sedation was deemed confusing, ambiguous, and open to different interpretations, it was argued that it should be abandoned altogether.<sup>5,6</sup>

To prevent confusion with terminating human life and in an explicit attempt to dissociate this practice from euthanasia, new wording was proposed, such as “controlled sedation” and “sedation for intractable distress in the dying.”<sup>5,7</sup> But the term that found its way into the scholarly literature was “palliative sedation.”<sup>8,9</sup> Recommendations, guidelines, and standards for the appropriate implementation were issued by national and international organizations, all which emphasize the ethical differences between palliative sedation and euthanasia. Examples include the guideline of the Royal Dutch Medical Association (RDMA) originally published in 2005 and revised in 2009,<sup>10</sup> the recommendations of the National Ethics Committee of the Veterans Health Administration (NEC-VHA) issued in 2007,<sup>11</sup> the international framework published in 2009 by the European Association for Palliative Care (EAPC),<sup>12</sup> and the position statement of the National Hospice and Palliative Care Organization (NHPCO) from 2010.<sup>13</sup>

But these developments have not subdued the controversies. Opponents continue to challenge the dominant view and not without cause. In this article, we discuss the dominant view that palliative sedation and euthanasia are categorically different practices and the challenges against that view. We compare and contrast theoretical perspectives and actual practices, showing that the latter often digress from the former, further fueling the aforementioned controversies.

### *The Dominant View*

The NEC-VHA has defined palliative sedation as “the administration of nonopioid drugs to sedate a terminally ill patient to unconsciousness as an intervention of last resort to treat severe, refractory pain or other clinical symptoms that have not been relieved by aggressive, symptom-specific palliation.”<sup>11(p484)</sup> The NHPCO describes palliative sedation as “the lowering of patient consciousness using medications for the express purpose of limiting patient awareness of suffering that is *intractable* and *intolerable*.”<sup>13(pp914,915)</sup> The scope of the NHPCO statement is limited to patients who are imminently dying.

These definitions and the many others in the palliative care literature not only reveal significant differences but also express several agreed-on characteristics of palliative sedation: its aim is to relieve refractory symptoms; this aim is accomplished by lowering the patient’s consciousness; the means used to achieve this outcome are sedative drugs; it is not an isolated intervention but a symptom control strategy within a palliative care trajectory; and it can only be used as an intervention of last resort.

In the aforementioned two definitions, the ethical differences between palliative sedation and euthanasia are implicit. They become more explicit in the definition proposed by Broeckeaert and Nunez Olarte:<sup>9(p170)</sup> “Palliative sedation is the intentional administration of sedative drugs in dosages and in combinations required to reduce the consciousness of a terminal patient as much as necessary to adequately relieve one or more refractory symptoms.” This definition captures the main elements listed previously and emphasizes several additional elements that are important for the ethical assessment of palliative sedation and that are reiterated in subsequent publications:<sup>14–17</sup> sedation is not itself the aim of the intervention but merely a means; the aim or intent is to relieve symptoms (and not to render the patient unconscious, let alone end the patient’s life); thus, the patient’s consciousness shall be lowered only as much and as long as necessary to relieve the symptoms; hence, all types of sedation are captured in the definition (continuous/intermittent, reversible/not reversible, and mild/deep); this

intent is not merely a matter of the subjective wishes of the health care provider but is evidenced by the manner of administration; specifically, the administration of the drugs is titrated according to the need to relieve symptoms (proportionality rule); the intervention is to be used when these symptoms are refractory, that is, they cannot be relieved with other means; and the intervention shall be used only when patients are terminally ill; the precondition for its application, therefore, is a very limited expected survival of the patient.

The differences between palliative sedation and euthanasia proclaimed by the aforementioned definitions can be made even more explicit if we consider not only what *is* palliative sedation but also what is *not* palliative sedation but euthanasia instead. The points of difference revolve around the intention, act (or intervention) itself, and outcome of the act.

In the case of euthanasia, the physician intends the death of the patient. Not only does the physician subjectively wish for the patient to die but also he or she selects types of drugs and dosages that are lethal by all objective measures. The physician next administers these drugs, making sure that the patient not only loses consciousness but also next ceases to breathe, followed by complete cardiac arrest. Only if this outcome is achieved, will the physician conclude that his or her intervention was successful.

In the case of palliative sedation, the intent of the physician is very different: not to kill but only to relieve otherwise unmanageable symptoms. This intent is evident from the fact that the physician will select drugs that have been proven to safely achieve sedation in other medical contexts (such as surgical anesthesia). Indeed, palliative sedation itself does not have a life-shortening effect on the patient. Death occurs at some point *after* symptom relief has been accomplished.<sup>13</sup> When the health care provider next administers these drugs, the dosage is carefully titrated to the intended effect, that is, symptom control. The desired outcome of the intervention is a lowered level of consciousness. If the patients were to actually die as a result of the administration of the drugs, then that would be considered an adverse outcome.

When palliative sedation is administered in the manner described previously, it is within

the range of palliative care practices. In contrast, euthanasia falls outside of that range for precisely the same reasons and, hence, is legally prohibited in most countries.

### **Contestations**

As already mentioned, the dominant view continues to be contested. Indeed, the demarcation between palliative care and euthanasia seems to be more debated nowadays than ever before. There appear to be two main reasons for the ongoing controversy.

#### *Moral Experience*

It was not too long ago that care for terminally ill patients was called "terminal care." Nevertheless, when the term terminal sedation was introduced, many associated the term with an intervention that terminates human life. The introduction of new jargon, replacing the term terminal sedation with palliative sedation, has clarified the distinctions between the concepts of sedation and euthanasia. But this name change could not itself change the experience of those at the bedside who saw the patient being sedated and, without ever regaining consciousness, expire not very long thereafter. Still other terms have been introduced such as total sedation, controlled sedation, deep sedation, end-of-life sedation, sedation for the imminently dying, and even therapeutic sedation. But none have been able to resolve the ambiguity of the experiences of those at the bedside, both family members and health care professionals.

Claessens et al.<sup>15</sup> have shown that 25% of families experience high levels of distress over the decision to initiate palliative sedation for a loved one. They believe that insufficient information about the process is provided; they complain about lack of compassion shown by physicians and nurses; they are concerned about ongoing suffering of the patient; and they fear that their decision has shortened the life of the family member. A survey among nurses in Flanders revealed that many health care providers likewise experience palliative sedation as an ethically problematic practice.<sup>18</sup> Of those surveyed, 77% thought that continuous deep sedation (CDS) was partly or explicitly intended to

hasten death. Only 4% believed that it had no life-shortening effect. Similarly, almost half of the medical specialists in Quebec surveyed in 2011 replied that palliative sedation can be likened to a form of euthanasia.<sup>19</sup>

These moral experiences do not prove that palliative sedation is tantamount to euthanasia. The ethical differences outlined before are analytically sound. But these experiences cannot simply be discounted either. We will return to this challenge in the following.

### *Practice Variation*

We have suggested that the heterogeneity of the terminology reflects attempts to demarcate sedation from euthanasia. The fact that the concept of palliative sedation emerged as the term of art would suggest that it also refers to one and the same practice only. But this presumption is questionable.

We saw earlier that the NHPCO advocates a restricted application.<sup>13</sup> Palliative sedation is to be administered only when the patient's suffering is intractable and intolerable. Furthermore, the aim of the sedation is symptom relief and not unconsciousness. Hence, sedation should be titrated to the minimum level of consciousness reduction that is effective at rendering the symptoms tolerable. For most patients, this will require less than total unconsciousness. A recent study in Belgium showed that in almost half of the patients receiving palliative sedation, the initial level of sedation was mild and intermittent and only in a later stage had to be increased to deep and continuous.<sup>16</sup> If these strict criteria are adhered to, palliative sedation, and particularly CDS to complete unconsciousness, will be used only rarely. Conversely, a high prevalence of palliative sedation and CDS would signify that this measure is not used as an option of last resort only but more likely as an alternative to other available palliative strategies.

Even a cursory review of the literature reveals striking differences in the reported prevalence of terminally ill patients undergoing palliative sedation, ranging from a mere 1%<sup>20</sup> to as high as 88%.<sup>21</sup> Exactly how many patients receive deep sedation is equally uncertain. In the study by Maltoni et al.,<sup>22</sup> a quarter of hospice patients in the Italian region of Emilia-Romagna received palliative sedation therapy,

but only a quarter of those received CDS. This statistic is consistent with other findings that 8.5% of dying patients in Italy received CDS.<sup>23</sup> But the same study showed that only 2.5% of patients in Denmark received CDS. In Flanders, the Dutch-speaking part of Belgium, CDS was used in 8.2% of cases in 2001. But this number was increased to 14.5% in 2007.<sup>18</sup> The U.K. exceeds even that statistic at 16.5%.<sup>24</sup> Besides variations by country, other studies have shown that the frequency of this type of sedation depends more on the habits of physicians than the clinical conditions of the patients.<sup>25</sup>

One of the evident explanations for these statistical variations is terminological polysemy. Many of the prevalence studies use different definitions of palliative sedation or no definitions at all. This variation is not unusual. As mentioned earlier, guidelines and protocols for palliative sedation abound, but they are inconsistent, too.<sup>26</sup> They differ on whether to consult the patient and family, whether to forgo life-sustaining interventions, and even on the drugs to be prescribed. It is little wonder, then, that morphine continues to be used in practice as a sedative agent, in spite of many guidelines insisting that it is not a sedative and, therefore, not appropriate.<sup>26,27</sup>

But these practice variations also may be associated with a more general phenomenon. Innovations and technologies are initially introduced in clinical practice within a carefully delineated context and for demarcated patient categories. But as the examples of dialysis and *in vitro* fertilization have shown, once introduced and found to be indicated for one specific category of patients, their application is gradually extended to other indications and other groups of patients.<sup>28,29</sup> This phenomenon, also known as "mission creep," appears to be happening in the area of palliative sedation as well, perhaps, as Broeck-aert<sup>17</sup> suggests because palliative sedation is no longer used only by palliative care specialists but has moved into general practice. Being less familiar with the latest arsenal of palliative care strategies, these general practitioners may use palliative sedation and even CDS more readily than a palliative care specialist would.

These practice changes have implications for the ethical debate. Representatives of

the dominant view tend to discuss this intervention in reference to persuasive paradigm cases, resulting in narrow definitions and strict criteria for its application. The demarcation with euthanasia is then clear. But as palliative sedation becomes more generalized and more sedative interventions are subsumed under its conceptual umbrella, the boundaries become less evident.

A case in point is the practice of palliative sedation as defined by Rietjens et al.<sup>30(p750)</sup>: “the administration of drugs to keep the patient in deep sedation or coma until death, without giving artificial nutrition or hydration.” In this definition, reduction of consciousness is not a mere means to achieving symptom relief. Instead, complete unconsciousness appears to have become itself the goal of the intervention. Furthermore, the sedation is to be sustained until death, again irrespective of its effect on the patient’s symptom relief. Critics argue, therefore, that this type of intervention conflicts with the guiding principle of palliative care, that is, titrated treatment of symptom control.<sup>31</sup> The explicit mention in the definition itself of the exclusion of nutrition and hydration leads critics to suspect that this practice is solely intended not only to bring about symptom relief but also to hasten the patient’s death.

These suspicions are fueled by empirical data showing that this type of sedation is not at all rare. In 2001, 4%–10% of all deaths in The Netherlands were preceded by this type of sedation (whereas 2.6% of all deaths are the result of euthanasia). When Dutch physicians were surveyed about their most recent involvement in palliative sedation, 17% responded that their explicit intention had been to hasten death (although in only 3% that intention guided their administration of the sedatives themselves, and in the remaining cases, it was their forgoing of artificial nutrition and hydration [AN&H] that was aimed at hastening death).<sup>30</sup> The most recent Dutch euthanasia study shows an increase of palliative sedation (12.3% of all deaths in 2010 up from 8.2% in 2005). It also concludes that there is major conceptual confusion: 18% of euthanasia cases (according to the strict legal definition of euthanasia) are labeled as palliative sedation by the surveyed physicians.<sup>32,33</sup>

### *Intention Revisited*

These practical realities have led some to conclude that CDS is a life-ending intervention that is ethically on par with euthanasia and physician-assisted suicide.<sup>34–36</sup> Rather than trying to hide this reality by adopting euphemistic labels such as palliative sedation, it would be more honest to use terminal sedation, thus Battin<sup>37</sup> (who appears to understand the adjective terminal to refer to the act of terminating rather than in the original temporal sense of in the final phase of life). Thus, the Dutch physicians who reported that the intention of their most recent sedative interventions was explicitly to hasten death should have labeled their actions as euthanasia rather than palliative sedation.

One has to wonder why so many physicians, even in a country that has legalized euthanasia and adopted a tolerant evaluative mechanism for euthanasia cases, elect to label their interventions as something other than euthanasia when those interventions both ethically and legally qualify as euthanasia. This is not, it should be emphasized, a new problem that has only arisen recently as palliative sedation has become more prevalent. Elsewhere, we have shown that, for decades, only a minority of Dutch euthanasia cases has been reported as such.<sup>38</sup>

Battin is, of course, correct in insisting on honesty. It is a prerequisite for any subsequent ethical assessment. But rather than expanding the definition of palliative sedation to include practices that are intended to bring about the patients’ death, it would make more logical sense to reserve the label “palliative sedation” for those sedative practices that are aimed *only* at symptom relief and apply the label “euthanasia” to *all* practices in which the patient’s end of life is the principal aim or at least one of the aims of the physician’s intervention.

It shall be clear that this theoretical distinction itself does not imply that it is easy or even possible in practice to engage in the former while avoiding the latter. For example, Rady and Verheijde<sup>34</sup> have argued that any attempt at CDS of any patient who is not already dying is inevitably marked by the intention to bring about the patient’s death.

Then again, on closer reading, it appears that Rady and Verheijde use a different

understanding of intention than is typically used by those advocating the aforementioned distinction between palliative sedation and euthanasia.<sup>39</sup> That distinction hinges on a narrow understanding of intention; that is, intention is the plan or aim that guides the action. In contrast, Rady and Verheijde understand intention much more broadly as awareness and knowledge of foreseeable consequences of an action. Likewise, one has to wonder whether the Dutch clinicians cited previously, when answering the question raised by Rietjens et al.<sup>30</sup> as to what their intent was while sedating their patients, understood that term broadly.

The foregoing observations underscore the importance of explicating both in theoretical debates about the morality of palliative sedation and at the bedside of the terminally ill patient exactly how those present understand the concept of intention. There is ample evidence that it is often very difficult for clinicians and lay caregivers alike to clarify and articulate the intentions that guide their actions.<sup>40,41</sup> That clarification is possible is shown by a recent study among euthanasia consultants in The Netherlands. The majority of them had received additional training in palliative care. Most of them indicated that the practice of CDS is clearly different from euthanasia because the intent of the intervention is different.<sup>42</sup>

A final comment on the concept of intention: It is important to underscore that the distinction between palliative sedation and euthanasia does not itself entail a moral approval of the former and rejection of the latter. The only thing that it does is classifying these two practices by their divergent intentions. Obviously, the aforementioned Dutch euthanasia consultants are not opposed to euthanasia; they consider it morally permissible to engage not only in palliative sedation but also in actions aimed at the death of the patient. In contrast, others may consider a palliative intent decisive for the morality of end-of-life medical interventions. In order for any such intervention to be morally permissible, it may *not* be aimed at the patient's death.

### ***Additional Ethical Parameters***

Regardless of their views on the moral significance of intent, virtually all advocates of

palliative sedation agree that additional moral factors must be considered when evaluating this practice. The four factors most often mentioned are 1) terminality, 2) refractory symptoms, 3) proportionality, and 4) separation of decisions about forgoing treatment.

#### *Terminality*

Many guidelines emphasize that palliative sedation should only be used for patients in the last stages of life. For example, the RDMA guideline sets a prognosis of death within 14 days as a condition for palliative sedation.<sup>10</sup> Some have even added the condition of terminality to the name by introducing the concept of "end-stage palliative sedation."<sup>27</sup> But prognostication is often inaccurate; research has long shown that physicians are notoriously bad at predicting the time of death.<sup>43</sup> As a result, patients with severe refractory symptoms who could benefit from sedation may not be offered palliative sedation when the physicians are not certain that they are terminal. This could explain why patients with cancer are more often offered palliative sedation than patients with other types of terminal illnesses.<sup>44</sup> The question thus arises why palliative sedation, when an effective response to unbearable suffering, should be available only to patients who are dying?

The main reason to restrict it to the very last phase of life is that palliative sedation carries significant risks.<sup>11</sup> It leads to impairment or complete loss of the patient's ability to interact and communicate with family and friends; it can create paradoxical agitation; and it causes distress among family and health care providers. However, the major risk, cited particularly by critics of CDS, is that it hastens death by suppressing vital functions.<sup>12,34</sup>

For a long time, especially in the early stages of the debate, this concern was widespread. The principle of double effect was used by advocates of palliative sedation to justify the practice in spite of this risk. In a nutshell, the principle of double effect states that an intervention that has a foreseen bad outcome can nevertheless be morally permissible provided the intervention is not intrinsically evil, the bad effect is neither intended nor the means for achieving the good effect, and the good effect outweighs the bad effect. Hence, as long as the sedatives are titrated and administered to

only relieve intractable suffering, the risk of hastening death is a tolerable side effect.

However, more recent research suggests that palliative sedation has no impact on the length of life when the patient is already close to death, and hence, the sedation lasts two to four days only as is true in the overwhelming majority of cases. In a recent Belgian study, palliative sedation was found to have been initiated on average only 2.5 days before the patient's death.<sup>16</sup> Also, a retrospective meta-analysis performed in 2011 found the mean across the six studies reviewed to be 1–3.5 days.<sup>45</sup> The survival rates between patients who received palliative sedation and those who did not are the same.<sup>22</sup> Even deep sedation may not have the life-shortening impact that some authors are worried about. Several studies suggest that deeply sedated patients do not die sooner than nonsedated patients, at least not as a result of the sedation itself.<sup>46,47</sup> Therefore, it can be concluded that the principle of double effect is no longer necessary to justify the use of palliative sedation.<sup>48</sup>

### *Refractory Symptoms*

We saw earlier that the Dutch national guideline restricts palliative sedation to patients who are terminal; it also restricts this intervention to patients whose symptoms are refractory.<sup>10</sup> This emphasis on refractoriness has led to three important debates.

The first concerns the nature of these refractory symptoms. The term “refractory symptoms” suggests that palliative sedation is generally seen as a treatment for somatic pain and other physical maladies, the severity of which can be determined objectively by the physician. Indeed, severe pain and dyspnea are most often reported as the reasons for initiating continuous sedation in The Netherlands.<sup>49</sup> Terminally sedated patients also more often tend to be very ill.<sup>30</sup> In contrast, requests for euthanasia are mostly related to patients' subjective sense of demise and loss of dignity.<sup>30</sup>

However, on closer examination, the concept of refractory symptoms is less clear. For example, Cherny and Portenoy<sup>7(p31)</sup> have defined a refractory symptom as “a symptom [that] cannot be adequately controlled despite aggressive efforts to identify a tolerable therapy that does not compromise consciousness.” This definition is silent on the causal nature of the symptom. Mental as opposed to physical

symptoms, therefore, could fall under this definition as well.

This definition by Cherny and Portenoy also makes clear that refractoriness, although appearing to involve a medical judgment, ultimately can only be decided by the patient, for only the patient can assess what is tolerable.<sup>50</sup> Thus, the question arises—which is the focus of the second debate—whether patients' suffering must be objectively measurable or can be existential and hence subjective; that is, whether the suffering must be neurocognitive in nature or also can be agent-narrative suffering.<sup>51</sup> The EAPC framework considers sedation appropriate for severe non-physical symptoms.<sup>12</sup> On the other hand, the NHPCO failed to reach agreement on the issue of existential suffering.<sup>13</sup> Many other guidelines and authors regard existential distress a controversial indication.<sup>12,13,52</sup>

The NEC-VHA<sup>11</sup> discusses several of the reasons for this controversy, including the concern that 1) relief of existential suffering is not a proportionate goal of sedating a person to unconsciousness and, more absolutely, 2) relief of existential suffering is not within the goals of medicine. An additional concern, as explicated by the NHPCO, is that existential suffering may occur earlier in the disease trajectory and long before death is imminent, which leads us back to the stated concerns about the patient being terminal.<sup>13</sup>

Notwithstanding its controversial nature, recent reviews of the literature on palliative sedation show that 27% of the studies mention existential suffering as a reason for sedation.<sup>15,53</sup> Indeed, it is not clear and certainly not self-evident why palliative sedation is only a justified response when the patient's suffering has “a direct causal relationship to the patient's underlying medical condition.”<sup>51(p324)</sup> Emphasizing the primacy of biology (the body as opposed to the whole person) in delineating appropriate indications for palliative sedation not only reiterates the dichotomy between body and mind and between the physician's perspective and the patient's perspective but also introduces a reductionist understanding of palliative care.<sup>54</sup> It is exactly this kind of somatic reductionism that the palliative care paradigm has adamantly sought to overcome, insisting that symptom distress and suffering go together.<sup>16</sup> Every medical

condition becomes a source of suffering only when and because it is experienced as such by the patient. And that experience, in turn, is inevitably colored by the meaning and interpretation that the patient assigns to these symptoms.

It follows from these reflections that the decisive factor is not the material nature of the symptoms but their refractoriness. Compared with psychological and, even more so, existential suffering, it may be easier to ascertain that, and when suffering rooted in somatic pathology is refractory, that is, when such pain fails to respond to all available drugs and other physical therapies. But the morally relevant factor here is not the source of the suffering but its refractoriness.

This consideration gives way to the third debate: What is the source of the refractoriness? Guidelines usually underscore that refractoriness is not a criterion in and of itself. It is dependent on the quality of care. Advanced knowledge of symptom management and palliative care expertise can often render palliative sedation unnecessary. It is, or should be, an exceptional treatment when symptoms are not susceptible to any alternative treatments.

There is yet another more nefarious way in which symptoms can become refractory. Rather than the lack of medical expertise, the cause of such refractoriness is the urge to find a less time consuming and hence less costly form of end-of-life care. There is no question that sedating a patient to unconsciousness is a far cheaper form of relief than a comprehensive package of physical therapy, nursing care, spiritual support, and various carefully titrated pharmacological forms of symptom relief. By the same token, deep sedation also is far less demanding on family members' schedules when they no longer need to spend time at the bedside accompanying the patient on his or her final journey.

Whether these factors in fact drive or at least contribute to the practice of palliative sedation has yet to be assessed empirically. However, contemporary end-of-life care is now heavily commercialized, especially in the U.S.<sup>55,56</sup> Yet the financial objectives of the new for-profit hospice industry are frequently at odds with the goal of compassionate service to the dying.<sup>57</sup> Available data suggest that, compared with nonprofit hospices, for-profit hospices,

to generate higher revenues, offer a narrower range of services, use less expensive labor, and select patients based in part on their likelihood to generate high reimbursements.<sup>58–60</sup> From a commercial perspective, palliative sedation may be attractive because it is a codifiable intervention (which is more likely to generate reimbursement income from Medicare and private health insurance), and it cuts back on the need for comprehensive and continuous comfort care measures.

### *Proportionality*

The statements of NHPCO, NEC-VHA, and EAPC argue that proportionality is an essential characteristic of palliative sedation.<sup>11–13</sup> In ethical discussions, the demand of proportionality can mean one of two things. First, it can refer to the balance between beneficial and harmful outcomes. An intervention is considered disproportional when the latter outweigh the former. The dominant view holds that unconsciousness is a serious harm indeed, and hence, palliative sedation must always be an intervention of last resort for refractory symptoms, but the benefit of relief from such symptoms can outweigh the harm of unconsciousness. However, some commentators have voiced concern that deep and permanent sedation “deprives the patient of consciousness at that most important moment of life, the moment of death, when conscious decisions may have eternal consequences.”<sup>61</sup> More generally, the loss of a person’s “higher faculties” induces a state “unworthy of a human being,” thus the Vatican Pontifical Council for Health Pastoral Care has warned.<sup>62</sup> Although not completely ruling out palliative sedation, the Council concludes that “the administration of narcotics for the sole purpose of depriving the dying person of a conscious end is a truly deplorable practice.”<sup>62</sup>

Second, and more commonly, when the demand for proportionality is raised in discussions about palliative sedation, it refers more narrowly to the *level* of sedation applied: This level must be proportional to the severity of the symptoms. The goal of palliative sedation is not to induce coma or bring the patient into deep sleep but to relieve the symptoms. For some patients, this will only be possible when they are rendered completely unconscious. But this is the outcome of a treatment

trajectory; the need for it can rarely if ever be known in advance.

As we already saw in reference to the aspect of terminality, here, too, some commentators have proposed to incorporate this criterion of admissibility of palliative sedation into the name: “proportionate palliative sedation” (PPS).<sup>63,64</sup> This concept is then distinguished from “palliative sedation to unconsciousness” (PSU)—which is a somewhat unfortunate label because PPS can give way to deep sedation to unconsciousness when lower dosages of sedatives have been shown to be ineffective. Therefore, the distinguishing characteristic between PPS and PSU is not the unconsciousness but the proportionality, or lack thereof, between dosage and symptoms. PPS provides the minimum amount of sedatives necessary for relief of suffering, whereas PSU seeks to bring about unconsciousness through immediate maximal sedation.

If a much higher dosage of sedatives is administered than is necessary to effectively relieve the patient’s symptoms, the question inevitably arises as to why this is done. Berger has argued that PSU is justified as a preemptive intervention. He describes a case in which mechanical ventilation is to be withdrawn from a patient with amyotrophic lateral sclerosis and PSU is administered to prevent dyspnea, which is expected to be severe. Berger contends that, for “patients seeking complete symptom control without delay and who do not value preservation of consciousness,” proportionality is not an ethically valid criterion.<sup>65(p804)</sup> But once this criterion has been discarded, it becomes difficult to demarcate palliative sedation from euthanasia.

#### *Separation of Palliative Sedation From Other End-of-Life Care Decisions*

The former three criteria covered the conditions under which palliative sedation may be morally permissible. The fourth and final criterion covers not so much palliative sedation itself but other end-of-life care decisions (and specifically decisions to forgo life-sustaining treatments) that are either typically made in conjunction with palliative sedation or evoked by a decision in favor of palliative sedation. The standard position in most guidelines is that the decision to provide palliative sedation should be separated from the decision to forgo

life-sustaining treatment.<sup>12</sup> The NEC-VHA<sup>11</sup> and NHPCO<sup>13</sup> argue that patients should have a do-not-resuscitate order, but they reject the view that palliative sedation should only be used when patients are willing to forgo cardiopulmonary resuscitation (CPR) and all other life-sustaining treatments.

Most patients who are candidates for palliative sedation are suffering from such severe illnesses that CPR is virtually futile. Hence, the decision to forgo CPR tends to be relatively noncontroversial in such circumstances. The same is true for still more complex interventions, such as dialysis. In fact, the controversy tends to be focused on one intervention only: AN&H. When patients are sedated to a depth and duration that precludes oral intake of food and fluids, the question arises whether such patients should be provided AN&H. The RDMA in its guideline insists that fluids should not be given to deeply sedated patients.<sup>10</sup> But this is exactly what leads critics to conclude that CDS is tantamount to euthanasia.<sup>34</sup>

The use of AN&H in sedated patients varies among countries. In Italy, 35% of these patients did not receive AN&H, and this was 64% in The Netherlands.<sup>23</sup> The introduction of the aforementioned national guideline on palliative sedation by the RDMA led to significantly more instances of AN&H being withheld or withdrawn (78.8%, up from 56.3%).<sup>49</sup> A recent study in Belgium showed that only 25% of sedated patients received fluids artificially on admission and 15% continued to receive AN&H until the day of death.<sup>16</sup>

What are the arguments for not giving AN&H to deeply sedated patients? One argument is that providing AN&H will be futile or even harmful to patients. When patients approach the end of life, they tend to drink and eat ever less. Continuing or starting AN&H during palliative sedation can be contraindicated when the balance of harms and benefits for the patient is taken into account. But in this context, the decision to forgo AN&H is independent of the decision to initiate palliative sedation.<sup>16</sup>

The second argument against AN&H is that it does not impact survival. Research shows that when the life expectancy is less than two weeks, forgoing AN&H does not hasten death.<sup>27</sup> But when life expectancy is longer,

life may well be shortened as a result of dehydration.<sup>10</sup> This leads us back to the earlier discussion of terminality. But here again, the discussion about administering palliative sedation can and should be separated from the discussion about forgoing AN&H. Moreover, for the ethical analysis, it makes a difference whether health care professionals administer an intervention that might hasten death or forego one that might sustain life.

Should it be concluded that AN&H may not be forgone except when it is clearly futile, this may lead to the conclusion that palliative sedation cannot be administered except when the patient is terminal or even imminently dying. Thus, Miccinesi et al.<sup>23</sup> speculate that the tendency to combine palliative sedation with AN&H in Catholic countries like Italy can be explained by the Church's insistence on the administration of AN&H. However, this conclusion does not concern the moral status of palliative sedation itself but only the morality of AN&H.

Then again, if health care professionals advocate immediate deep sedation to unconsciousness (as opposed to proportional sedation titrated to the patient's symptoms) for a patient with existential suffering that has yet to be addressed with alternative forms of relief, and this patient has a life expectancy of a month or longer, and they also insist on forgoing AN&H, it will be rather difficult for these professionals to argue that their intent is solely to relieve the patient's symptoms and not to hasten death.

### ***The Possible Impact of Palliative Sedation on the Palliative Care and Hospice Philosophy***

The growing debates about the ethics of palliative sedation over the last two decades not only reflect concerns on the part of the palliative care community but also about the moral status of that particular intervention. The full incorporation of palliative sedation into the palliative care arsenal also may impact and transform the nature of palliative care itself.

Palliative sedation is generally regarded as a therapy (sometimes even labeled as PST [palliative sedation therapy]) or at least as a medical treatment that requires special expertise.

Controlled sedation was first described for patients in intensive care units,<sup>66</sup> and it has retained this association. It thus was considered part and parcel of traditional medical end-of-life care, instead of being categorically different in the manner in which hospice care has traditionally proclaimed itself to be.<sup>67</sup>

But this understanding of palliative sedation is no longer borne out by actual practice. We already cited the observation by Broeckaert<sup>17</sup> that palliative sedation has moved into general practice. In Belgium, the incidence of palliative sedation in specialized palliative care units is actually lower (7.5%) than that in general care settings (14.5%).<sup>16,68</sup> In a recent Italian study, Mercadante et al.<sup>69</sup> found that palliative sedation was used in 13.2% of patients cared for in their homes. The 2010 Dutch study cited earlier showed that 43% of palliative sedation interventions were applied by general practitioners and only 38% by medical specialists.<sup>33</sup> Another Dutch study concluded that CDS is increasingly considered as part of regular medical practice.<sup>70</sup>

This shift in the practice of palliative sedation—from a limited and restricted intervention practiced only by a relatively small number of intensivists and palliative care specialists to a more widely and liberally applied intervention practiced by general practitioners—may have several important ethical consequences. The first involves a return to silence. Back in 1969, Kübler-Ross argued that we should break the silence about death and dying. We should talk about the experiences in which we all will participate.<sup>71</sup> Around the same time, Saunders<sup>72</sup> defined care for dying patients as an intersubjective process, a shared journey that requires that we listen attentively to the patient. Palliative care, therefore, is regarded as a quintessentially relational approach.<sup>73</sup> The original hospice philosophy underscored the importance of connectedness, community, inclusion, and belonging.<sup>74,75</sup> A chair rather than a bed was the most important piece of equipment in ward rounds. In contrast, the practice of palliative sedation brings us back to the days of old in which dying takes place in silence. Patients are sleeping instead of communicating. A recent observational study in a Nordic hospice confirms this dissipation of the hospice philosophy: the wards are quiet, the patients alone in their rooms, and the staff is busy.<sup>76</sup> We hasten to

emphasize that this silence was not the result of all patients being sedated. But the authors do speculate that the intervention-oriented medicalization of palliative care, of which palliative sedation is a paradigmatic example, contributed to this return to silence.

Second, the hospice philosophy emphasized the need for a holistic approach to human suffering. Saunders<sup>67</sup> introduced the concept of “total pain” to express the complex of physical, emotional, social, and spiritual elements. In contrast, palliative sedation suggests a return to medicine’s traditional focus on the physical dimension of suffering and a physical response thereto, as affirmed in a recent editorial: “It is far easier to increase the dose of midazolam than it is to wrestle with the underlying issues of a patient’s care.”<sup>77</sup> Palliative sedation can be viewed as the successor to the Brompton Cocktail, a mixture of morphine, cocaine, alcohol, syrup, and chloroform water that was believed to have near mystical healing powers. Widely used until the end of the 1970s,<sup>78</sup> even Saunders in her first publication from 1958 wrote enthusiastically about its value. It induced transient sedation and assured a calm transition to death. The problem with any quick fixes such as the Brompton Cocktail and palliative sedation is that they fail to address the complexity of human suffering. In this regard, they actually are akin to euthanasia, which likewise circumvents human suffering by simply ending the patient’s life.

## Conclusions

In this article, we have argued that palliative sedation can be clearly demarcated from euthanasia, provided the intervention is indeed sedative in nature, that is, aimed at and designed to reduce the patient’s consciousness of severe symptoms. The sedative intention is related to and evidenced by adherence to various ethical parameters: The sedatives may be administered only when the symptoms have become intractable, in accordance with the principle of proportionality, and when the patient is terminal such that the expected loss of life is nil or minimal.

However, we also have shown that, in actual practice, the clear demarcation between palliative sedation and euthanasia is dissipating. The

reasons are many. In part, the dissipation is caused by widespread puzzlement among clinicians about the meaning and significance of the ethical concept of intent. But we have seen that this factor can be countered effectively through targeted education.

Most difficult to manage is the “mission creep” that appears to be occurring. A proliferation of sedative practices far beyond the original case of palliative sedation is indicative of and fueled by widespread and culturally anchored convictions about the meaning of aging, vulnerability, dependence, suffering, and dying. And, these are once more the same convictions that drive the euthanasia practice.

As a result of this mission creep, the field of palliative and hospice care itself is changing. We are actually witnessing a vanishing of the original hospice philosophy as a result of the incorporation of palliative sedation. Present-day palliative end-of-life care is reiterating the very characteristics of the traditional medical approach to end-of-life care that motivated the development of the hospice movement in the first place: the focus on therapy rather than care, the physical dimension rather than the whole person, the individual patient rather than the community, and the primacy of intervention rather than receptiveness and presence. Euthanasia, although often presented as an alternative to the traditional medical approach to the end of life, paradoxically has the very same focus.

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