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# How to overcome the ethical challenges of palliative care sedation

## 5 key factors to consider during end-of-life care

Caring for terminally ill patients presents unique ethical challenges for clinicians, particularly when it comes to deciding whether sedation is effective or even necessary. It is important to understand the [medical ethics](#) involved in end-of-life care, which patients qualify for sedation (and at what point), and which medicines are effective in this process.

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### 1. Learn what refractory symptoms palliative care sedation is for

End-of-life patients experience a variety of symptoms that can be frightening for their loved ones to witness, explained French researchers led by Cédric Daubin in "[Ethical reflections on end-of-life signs and symptoms in the intensive care setting: a place for neuromuscular blockers?](#)," including gasping, visual or auditory hallucinations, excessive respiratory secretion, myoclonic jerks, and severe diarrhea.

In "[National Hospice and Palliative Care Organization \(NHPCO\) Position Statement and Commentary on the Use of Palliative Sedation in Imminently Dying Terminally Ill Patients](#)," Timothy W. Kirk et al. describe the most common refractory symptoms that result in palliative care sedation, including:

- Pain
- Dyspnea
- Delirium
- And restlessness "declared by the patient — or the patient's surrogate — to have risen to the level of intolerable suffering"

They mention proximity to death as an important qualifier but also acknowledge that "there may be some situations in which patient suffering is so severe and refractory to other interventions that proximity to death becomes far less important than the relief of suffering itself."

However, [Daubin and the other researchers acknowledge](#) that,

"End-of-life signs and symptoms pose a difficult problem through how they are seen, interpreted, and represented, notably in terms of possible suffering experienced by the patient. Faced with a patient prey to disturbing manifestations of a prolonged dying process, those present (caregivers and

loved ones) are confronted by their own powerlessness and finiteness.”

## 2. Investigate whether palliative care sedation treats pain — or just perceived pain

Indeed, it's at least in part the comfort of caregivers and loved ones to which palliative care sedation caters. [Daubin et al.](#) discuss the case of a mother who witnessed her end-of-life fourteen-year-old daughter encounter agonal respiration preceding death:

“The mother said that she wished she had not seen her daughter gasping, that she was convinced that her daughter had suffered and that in her dreams she frequently relived her daughter's last unbearable moments. [...] Among the many arguments [for palliative sedation,] two are particularly worthy of our attention since they lie at the heart of the dilemma facing caregivers[.]

1. What a patient may or may not feel in the gasping phase of the dying process
2. The obligation felt by caregivers to alleviate the distress experienced by the patient's loved ones for whom the suffering perceived in the gasping respiration becomes intolerable.”

Though the symptoms are frightening, [Daubin et al. question](#) whether gasping causes pain:

“Everything suggests that gasping patients do not feel pain or respiratory discomfort since clinically there is no objective evidence of residual consciousness. [...] At this stage of the dying process, medication offers nothing and should give way to support not only of the dying patient, but also of the patient's loved ones.”

Not all palliative cases are appropriate for sedation. In [this continuing medical education session on palliative care](#)

[sedation](#), Dr. Steven M. Smith explores three cases with potential for end-of-life sedation, including:

1. An 18-year-old male on a high dose of opiates with end-stage cancer demonstrating significant decline, severe pain, worsening delirium, and an inability to eat or drink.
2. A 12-year-old patient in concurrent care hospice with a neurodegenerative disorder. Overall stable with optimized medical management, but worsening agitation.
3. A three-year-old patient removed from ventilatory support with neurological impairment, low symptom burden, and a prognosis of days. The patient's parents are concerned about unnecessary suffering.

While Smith explains that the first case is the most straightforward for effective palliative care sedation, the other two present unique challenges with which physicians caring for end-of-life patients should be familiar — especially considering [ethical challenges in pediatric palliative care](#) that can also apply to adult care. [Daubin and the other authors continue:](#)

“What is to be done? Shorten [...] the last convulsions, which are often seen as violent manifestations of a body locked in a final battle against certain and imminent death? [...] Or instead respect this ultimate moment of life, this unique and singular time that everyone should be able to live through, without having their last moments of life purloined, whatever the cost to loved ones and caregivers?”

## 3. Understand the ethical challenges of palliative care sedation

Ethically speaking, what do clinicians owe to patients' loved ones watching the process of death? [Daubin and the other authors suggest](#) that clinicians:

- “Explain, describe, and inform so as to shed light on this demise and to inscribe it in the natural process of life.”
- Avoid being “ill at ease” and instead appear “supportive” and able to speak of what is happening as a troubling but natural phenomenon [to] contribute to a greater acceptance [...] of these end-of-life signs.”
- Choose your words carefully “as [some relevant medical terms] have highly negative connotations.”

Palliative sedation is a rare time when clinicians may have the impulse to prioritize the comfort of caregivers and loved ones over the patient themselves. [Daubin et al. suggest](#) there is,

“A shift in ethical aim, which initially targeted the patient and now focuses on loved ones. [...] But how far can we protect others from the terrible impact of the death of a loved one? What [authorizes] an act that no longer has any therapeutic purpose, nor even is intended to improve the patient's comfort?”

Concerns about whether dying patients actually feel better post-sedation are valid. In their review of mostly cancer patients, “[Palliative pharmacological sedation for terminally ill adults](#),” Elaine M. Beller et al. indicate “there was insufficient evidence about the efficacy of palliative sedation in terms of a person's quality of life or symptom control.”

Some suggest that palliative care sedation is ethical under Catholic ascetic St. Thomas Aquinas' doctrine of double effect, which [Hannah Faris et al. explain](#) “justifies doing a ‘good action’ with a potentially ‘bad effect.’” But, as Faris and the other authors explain, since end-of-life sedation may “[hasten] death” or otherwise stymie the patient's experience of the end of their own life, this doctrine cannot be ethically

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applied in the case of palliative care sedation and simply “reflects the medical community’s discomfort with the (moral, medical, political) complexities of end-of-life decision-making.” In terms of hastening death, [Beller et al. published](#) findings suggesting “survival time from admission or referral to death [...] demonstrated no statistically significant difference between sedated and non-sedated groups” but also acknowledge that “this evidence comes from low-quality studies, [and] should be interpreted with caution.”

Daubin and the rest of the [French research team](#) agree that palliative care sedation with neuromuscular blockers presents a significant philosophical and ethical conundrum since,

“The dying patient remains a person who cannot be reduced to a thing, despite appearances. [Are they not still] a body which continues to lead its own existence, to manifest life by movement and sound? [...] Do we wish to control the uncontrollable, to preserve mastery over a natural process, over an eminently human moment [?] Is it a symbolic wish to sacrifice the dying person who is already no longer seen as who he was, but instead as neither really alive nor dead, neither body nor corpse, in a somewhat utilitarian attempt to procure less disquiet for the greater number? Laudable though it may be to seek to comfort those who live through the tragic experience of the death of a loved one, is not the use of muscle relaxants in the terminal phase also a way to spare us from thinking about dying and especially its clinical implications? Neuromuscular block [is] used to avoid the confrontation with death, as if to escape death, in a way to die without dying, that is to die as we fall asleep, soundlessly, without signs, without excess, discreetly [but] death cannot be avoided: sooner or later, here or elsewhere, it will happen. What then are we seeking



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to mask [...] by inducing mortal paralysis, since we suppose that the patient is beyond all suffering and anguish, which is exactly what is enabled by neuromuscular block, while it would be very hard to imagine the same for a conscious person? [...] The purpose is to mask the truth of what is happening: the end of life of an individual, with no benefit for the dying person.”

[Daubin et al. wrote](#), “Perhaps one day it will be proved that a patient in this state is already dead. [...] If this were to happen, muscle relaxants would pose no problem. Medicine would be nothing more than embalming the patient but would nonetheless [fulfill] its role towards

others.” However, recent findings by Sam Parnia et al. in “[AWAreness during REsuscitation - II: A multi-center study of consciousness and awareness in cardiac arrest](#)” surveyed survivors of near-death cardiac arrest and found that though “awareness is assumed absent during [cardiac arrest,] survivors reported perceived awareness, [...] transcendent experience, and [themes including] fear, persecution, and features suggesting emergence from coma.” Could this suggest that palliative care patients are also conscious past the point that we as clinicians have assumed? What would that mean for the ethics of palliative care sedation as a whole? Such questions are crucial to consider.

#### 4. Be aware that sedation techniques vary based on symptoms and conditions

[Daubin et al. explain](#) that symptoms “should be treated appropriately, or better still anticipated and prevented by specific care,” but it can be difficult to select the right medicine for palliative care and its associated symptoms. Certain medicines are considered capable of calming some of the “scarier” symptoms, [Daubin and the other authors explain](#): “at the stage of persistent gasping, only a muscle relaxant can act effectively on rales, hiccups and convulsions and bring to an end the sounds and contortions of a body struggling against inevitable death.”

As for the sedation itself, the medicine choices and dosage schedules vary for those with and without cancer, write Dr. Jesús Díez-Manglano et al. in “[Palliative Sedation in Patients Hospitalized in Internal Medicine Departments](#)”:

“Patients with cancer were more frequently administered rescue doses [and] patients with cancer had more pain, while the patients without cancer had more dyspnea. [...] It is possible that, when deciding to administer PS, clinicians and relatives assign greater value to relieving pain than to relieving dyspnea. [...] A surprising finding of our study was that the presence of anorexia and cachexia was associated with a lower use of PS.”

#### 5. Understand how to use common medicines for palliative care sedation and standardize dispensation based on validated instruments

In their review of medicines used for palliative sedation in Europe, [Díez-Manglano et al. note](#):

- “Midazolam was the most commonly used drug.”
- “Nevertheless, in a Chinese study, diazepam was used preferentially.”
- “Other nonsedative drugs such as morphine and butylscopolamine were also frequently used for our patients. Morphine, although not a drug for PS, should be maintained when it has previously been used as an analgesic.”
- “Adding scopolamine is recommended to prevent the onset of rales or to decrease their intensity. An initial dose of midazolam is usually necessary to induce PS. Maintenance doses should then be administered, preferentially in a continuous infusion.”

In “[How to measure the effects and potential adverse events of palliative sedation? An integrative review](#),” Alazne Belar et al. examine possible side effects of sedatives including delirium and pain in addition to the strength of the sedation itself. The authors suggest validated instruments for clinicians to take “a more standardized approach to assessing the effect of palliative sedation and possible adverse events, paying special attention to adequate training of health care professionals and timing of measurements [as well as documentation] to improve the quality of palliative sedation.”



Reviewing relevant continuing medical education courses on end-of-life care, from [palliative care in the ICU](#) to [how to respond to patient questions about physician-assisted death](#), can help you clear up patient misunderstandings including the conflation of euthanasia with palliative sedation. CME courses like these are critical to helping you provide patients with the most modern and ethical care available at the end of their lives.