Palliative Sedation: Assessment, Management, and Ethics

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Palliative sedation is used in the field of hospice and palliative medicine for the management of refractory symptoms; however, common misconceptions persist in the medical community and general public regarding its use. Palliative sedation can be an effective tool for controlling symptoms unresponsive to multiple forms of aggressive palliative interventions. Yet, without clear guidelines and proper informed consent, palliative sedation may cross some important ethical boundaries in medical practice. A lack of unifying terminology and clear indications to define the process has complicated clinical use and research. This article reviews definitions and clarifies important concepts underlying the practice of palliative sedation so that it can be implemented in an ethical, legal, and medically safe manner as needed.

TERMINOLOGY AND DEFINITIONS

One of the most prominent early terms for the use of medicines to sedate a dying patient was "terminal sedation," and this term is still commonly used to refer to this practice.[1] Because of the word "terminal" and its obvious negative connotations, some believe this term implies that the goal of sedation is death instead of a means to control difficult symptoms; thus, this terminology has fallen out of favor in the palliative medicine literature. "Total sedation" has also been used,[2] but as the procedure becomes more refined, some have called for describing varying levels of sedation (eg, deep or total sedation versus light or intermittent sedation).[3] The emerging unifying term has become palliative sedation.[4,5] The word "palliative" originates from the Latin word *palliatus,* meaning "to be cloaked or shielded." This helps to reinforce that the goal of palliative sedation is to relieve symptoms through sedation. Palliative sedation can be defined as a procedure to provide relief of intractable symptoms (ie, physical, psychologic, spiritual) by inducing an intentional state of decreased consciousness without intending death.[6] Additional terms that have been used for palliative sedation are listed in **Table 1**.

TAKE HOME POINTS

- Palliative sedation can be defined as a procedure to provide relief of intractable symptoms (ie, physical, psychological, or spiritual) by inducing an intentional state of decreased consciousness without intending death.
- Palliative sedation should be considered only after all other interventions have failed for 1 or more intractable symptoms.
- A palliative medicine physician and practitioners from other health care disciplines should be involved to assure that all possible interventions have been utilized.
- Informed consent should be obtained from the patient, or if the patient lacks decision-making capacity, a surrogate decision maker.
- Consider a trial of sedation for 24 to 48 hours to determine if sedation provides the symptom relief the patient desires.
- Good documentation and communication are essential to avoid misunderstanding of the intent of palliative sedation.

Chater et al[6] chose the term "sedation for the intractable distress in the dying" to describe palliative sedation and defined the procedure as deliberately inducing and maintaining deep sleep but not deliberately causing death in very specific circumstances: (1) for the relief of 1 or more intractable symptoms when all other possible interventions have failed and the patient is perceived to

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Table 1. Terms for Palliative Sedation

Palliative sedation (preferred term)
Terminal sedation
Total sedation
Sedation for intractable distress in the dying patient
Sedation for refractory symptoms
Euthanasia or slow euthanasia (not widely accepted as equivalent)
Physician-assisted suicide (incorrect)

be close to death, or (2) for the relief of profound anguish (eg, spiritual anguish) that is not amenable to spiritual, psychologic, or other interventions and the patient is perceived to be close to death.[6] Some have adopted this definition in the development of clinical practice guidelines.[7]

A key to understanding palliative sedation is to recognize what it does not entail. The common practice of prescribing sedatives (ie, benzodiazepines, barbiturates) or medicines that may cause sedation (ie, tricyclic antidepressants, antipsychotics, anticonvulsants, opioids) for basic symptom control is not palliative sedation, but instead basic end-of-life care. When a patient has a decreased level of consciousness, many mistake this common and natural occurrence in a dying patient to be a purposefully induced sedation. As they approach the end of life, patients are frequently fatigued and tired and may sleep a majority of the time with or without common palliative medications. Recognition of the normal process of dying is critical so that decreases in symptom control medications do not expose the patient to unnecessary suffering.

EPIDEMIOLOGY AND INDICATIONS

The actual practice of palliative sedation is difficult to study because there has been no consensus on the definition. Studies have reported that between 3% and 52% of patients have received palliative sedation.[8–10] The use of palliative sedation has also been reported in pediatric patients.[11–13] These studies are difficult to compare because of the lack of a unifying definition and differences between patient populations.

There is no single refractory symptom that indicates when palliative sedation should be initiated. **Table 2** lists the prevalence of symptoms in patients who received palliative sedation in a recent study by Kohara et al.[14] Despite the number of symptoms that palliative sedation can control, it is never intended to be a first-line palliative therapy. The primary indication for palliative sedation is to control refractory symptoms and does not include symptoms that are merely difficult to manage.

Table 2. Symptom Prevalence in Terminally Ill Patients Receiving Palliative Sedation

Symptom	Prevalence, % (N = 63)
Dyspnea	63
Malaise/restlessness	40
Pain	25
Agitation	21
Nausea/vomiting	6
> 1 symptom	54

Data from Kohara H, Ueoka H, Takeyama H, et al. Sedation for terminally ill patients with cancer with uncontrollable physical distress. J Palliat Med 2005;8:20–5.

Before palliative sedation is considered, the patient should be given access to multiple palliative therapies, preferably under the consultation of a physician with expertise in symptom control. Before sedation is used as a method of symptom control, other attempts at symptom control should have failed or ineffectively controlled the symptom within a reasonable time frame, or they should present a greater burden than benefit to the patient.[5]

Refractory physical symptoms (eg, pain, vomiting, dyspnea) or psychologic symptoms (eg, anxiety, agitation) are easily recognized and understood as an indication for palliative care. However, some physicians feel palliative sedation may not be appropriate for relieving spiritual anguish or existential suffering. Although hospice and palliative literature espouses that total pain assessment encompasses physical, psychologic, and spiritual arenas, applying this concept to each of these categories of pain has been difficult. Although the suffering associated with loss of meaning and independence at the end of life can be more distressing to patients than physical symptoms, the possibility of achieving transcendence or spiritual growth at the end of life by working through existential issues may prohibit hospice and palliative professionals from considering palliative sedation.

Palliative sedation is more appropriate when the patient is very close to the end of life, usually with a prognosis of hours to days. Some physicians become concerned with the ethical validity of palliative sedation the further a patient is from the prognostic end of life. However, physicians are notoriously inaccurate at prognosis of the end of life and are usually more optimistic in their predictions.[15] Palliative care physicians typically use the Palliative Performance Scale (PPS) as well as experience and clinical judgment to estimate life expectancy. The PPS is used to score a patient in 5 key areas (0%–100%): ambulation, activity, self-care, intake, and

level of consciousness. A PPS score of 30% or less usually indicates a prognosis of days after admission to hospice or palliative care units.[16–18] In a recent study, 83% of patients receiving palliative sedation had a PPS of 30% or less.[14] Common examination findings at the end of life include labile blood pressure, hypotension, decreased urine output, bradycardia, apnea of 5 s or longer, mottling, and coolness of the skin. Decreased appetite, energy, and interaction may also be present during the dying process.

MANAGEMENT

Clinical practice guidelines have been published to provide a more uniform approach to this potentially difficult procedure.[5,7] Similar to any other medical procedure, having a protocol prevents miscommunication, decreases risk, and ensures appropriate use. Four criteria for patient selection should be met before palliative sedation is considered (**Table 3**). As stated previously, the patient must have a terminal disease, death should be imminent (hours to days), and the patient's symptoms should be refractory. The important discussion of code status, completed by placing a do not attempt resuscitation order on the chart, should occur before a patient is given the option of palliative sedation.

After patient selection criteria are met, 4 additional steps should be completed by the health care staff, preferably by the physician directing palliative sedation (Table 3).[7] As the field of palliative medicine grows, it is becoming possible for physicians at academic and community medical centers to consult with experts in symptom management. If a palliative medicine specialist is not available, physicians should consider contacting the medical director of a local hospice agency, who is likely to be certified by the American Board of Hospice and Palliative Medicine. In addition to receiving a comprehensive medical evaluation, the patient should also have the opportunity to meet with physicians in multiple disciplines to explore alternative options for symptom control. A social worker, counselor, advanced practice nurse, or chaplain may be able to discover issues and offer solutions that are typically beyond the scope of a physician's practice or comfort.

A critical step prior to initiating palliative sedation is open discussion with the patient (if s/he still has medical decision-making capacity) and family members. The current medical situation, past ineffective therapies, unavailable therapies (due to risk, cost, or burden), and clinical goals of care should be discussed as these provide the basis of proper voluntary informed consent. The medical team should cover the ethical and legal aspects of palliative sedation to reduce the risk of misunderstanding, in addition to the standard informed consent discussion of risks, benefits, and alternatives. A separate meeting with key members of the health care team may also help avoid any potential disagreements about palliative sedation; this step is often overlooked when decisions are made regarding a particular treatment plan. A review of medications and treatments to be continued and withdrawn while undergoing palliative sedation should also be included in this discussion.

Table 3. Clinical Practice Guidelines for Palliative Sedation

Patient selection
A terminal disease must be present.
The patient must have refractory symptoms.
Death must be imminent (hours to days).
A "do not attempt resuscitation" order is placed on the chart.
Management
Symptom assessment: The patient has been assessed by a physician with expertise in symptom management to ensure the patients' symptoms are truly refractory. This step should include a multidisciplinary assessment when possible.
Voluntary informed consent: A discussion should be undertaken with the patient (if possible) and family regarding the goals of care, which includes the clinical, ethical, and legal ramifications of palliative sedation.
Technical competency: After informed consent, the patient will have sedation and proper monitoring for adequate symptom control.
Proper documentation: Criteria and rationale must be appropriately documented in the medical record.

Data from Braun TC, Hagen NA, Clark T. Development of a clinical practice guideline for palliative sedation. J Palliat Med 2003;6:345–50.

The use of artificial nutrition and artificial hydration during palliative sedation may be contentious.[19] Although artificial nutrition and artificial hydration may be continued during palliative sedation, the goals of providing these therapies may not be concurrent with relief of symptoms but rather may prolong the time before death. Many patients do not admit to suffering from hunger regardless of the amount of caloric intake near the end of life. In addition, artificial means of hydration and nutrition may cause more suffering because of volume overload, aspiration pneumonia, edema, and increased urine output and bowel movements. A more detailed discussion of withholding artificial hydration and artificial nutrition is beyond the scope of this article, but it should be addressed before palliative sedation is initiated.

Although there are many medicines utilized for sedation, there have been no controlled trials to document their efficacy in this setting. Benzodiazepines and

Table 4. Medications and Starting Doses for Intravenous/Subcutaneous Palliative Sedation

Medication	Initial Bolus	Continuous Infusion	Usual Maintenance Dose
Midazolam	0.5–5 mg IV/SC	0.5–1 mg/h IV/SC	20–120 mg/d
Lorazepam	1–5 mg IV/SC	0.5–1 mg/h IV/SC	4–40 mg/d
Haloperidol	1–5mg IV/SC	5 mg/d IV/SC	5–15 mg/d
Pentobarbital	2–3 mg/kg IV	1 mg/kg/h IV	NA
Phenobarbital	200 mg IV/SC	600 mg/d IV/SC	600–1600 mg/d
Propofol	20–50 mg IV in emergency	10 mg/h IV, titrate by 10 mg/h every 15–20 min	NA

NOTE: If possible, the health care professional should consult with a pharmacist and palliative care consultant before using these medications.

Adapted from Rousseau PC. Palliative sedation in the management of refractory symptoms. J Support Oncol 2004;2:185. Copyright © 2004, with permission from Elsevier.

IV = intravenous; NA = not applicable; SC = subcutaneous.

barbiturates are commonly administered in palliative sedation. Specific medications and dosing information are described in **Table 4**. These medications are usually administered by intravenous or subcutaneous drip so that medications can be easily titrated to the desired level of sedation. Administration of the drip is usually preceded by a bolus dose (Table 4).[4,20] The goal of titration is to find the most effective dose to achieve the desired level of sedation.

In addition, any opioids already prescribed should be continued to provide ongoing pain relief. It is a common misconception that initiating sedation is a reason to discontinue opioids. Because benzodiazepines and barbiturates do not directly provide pain relief, opioid doses should remain unchanged at the initiation of palliative sedation. Discontinuing opioids may precipitate opioid withdrawal or result in the patient having pain that goes unnoticed because the patient is sedated and unable to communicate.

Monitoring for palliative sedation is not to be compared with monitoring for sedation in intensive care unit patients. Testing for depth of sedation with frequent vital sign checks or checking response to stimulation by inducing pain through sternal rub or depression of the nail bed is unnecessary when treatment goals are palliation. A train-of-four, a device to test for neuromuscular blockade and depth of paralysis, is commonly used in the intensive care unit on patients who are also sedated, but this device is unnecessary in palliative sedation because patients are not medically paralyzed. Other diagnostic tests may also be limited, including complete blood counts and monitoring of glucose, continuous oxygen saturation, and arterial blood gases. The withholding of these tests should be discussed with the patient and family before initiating palliative sedation to avoid any misunderstandings of the goals of care.

A time-limited trial of palliative sedation or applying varying degrees of sedation may affect the intensity of assessment and monitoring the patient requires. A 24- to 48-hour period of palliative sedation has been termed "respite palliative sedation" and may be appropriate in some cases when the patient or family requests a trial of sedation and a possible return to consciousness to determine if the period of symptom relief gives the patient the rest they require.[21]

LEGAL AND ETHICAL ISSUES

Because palliative sedation has been inconsistently defined, some may confuse it with the controversial aspects of hastening death through medical means, specifically physician-assisted suicide and euthanasia. Altough euthanasia is not legal in the United States, physician-assisted suicide has been a legal and available option for terminally-ill patients in Oregon since 1997.[22] Palliative sedation is not considered euthanasia or physician-assisted suicide by most medical societies.[2,23,24] The United States Supreme Court has ruled in support of palliative sedation as a means of last resort for intractable suffering.[25,26]

The ethical basis for employing palliative sedation is based on a number of factors already described. The principle of autonomy is critical to proper implementation. For a patient without the capacity to make medical decisions, the autonomy component shifts to the surrogate decision maker as defined by law. Closely related to autonomy is the voluntary nature of palliative sedation, which is enforced by the informed consent of the patient or surrogate decision maker.

The doctrine of double effect is a common foundation of basic palliative care and supports palliative sedation. There are 4 rules of the doctrine of double effect, which is based on Catholic theology (**Table 5**).[1] First, the nature of the act must be good or morally neutral. In the case of palliative sedation, the act (ie, sedation),

when described alone, is morally neutral. Second, the intent must have a good effect, but a bad effect may be predicted and permitted. A common explanation for palliative sedation in these terms is that the intent to relieve symptoms is inherently good, but it is understood that in the process the patient may die. A similar logic is used when permitting extremely high-risk surgeries, where it is possible that the patient may die because of a potentially life-saving surgery. Third, the bad effect must not be the means to the good effect. Therefore, death (bad effect) is not the means to relieve symptoms (good effect), but rather sedation (the act) is. Last, the good effect must outweigh or equal the bad effect. One must balance the effects on the patient but also consider the effects on the family and health care staff. In this case, the goal of relieving refractory symptoms in a dying patient is perceived as something good to be achieved even when death may be imminent and unavoidable.

Physicians may perceive weaknesses in the ethical framework of palliative sedation and therefore may not be able to reconcile their personal ethics with palliative sedation. However, this does not mean that palliative sedation is no longer an option for a patient as long as the physician is willing to transfer care to a physician more comfortable with the procedure.

Some argue that it is difficult to prove the patient's intent in requesting palliative sedation or the physician's intent in providing palliative sedation. A strong effort should be made to explore the patient's intent if it is unclear. If the physician's intent is questioned, a very helpful tool is to consult with another physician. Another common argument against palliative sedation centers on whether all therapeutic options have been explored and exhausted. This issue can typically be countered by consultation with a palliative medicine specialist. The possibility that a patient may experience personal growth through suffering is considered by some a reason to avoid using palliative sedation as a means to relieve spiritual anguish. However, the decision regarding when a patient is no longer achieving spiritual growth ultimately belongs to the patient or surrogate decision maker.

Many of the pitfalls of implementing palliative sedation can be avoided with proper documentation and the use of clinical practice guidelines. Without either, health care professionals are vulnerable to interpretation of their actions without the support of written justification. Documenting each of the steps outlined in this article may help defuse any potentially difficult situation.

Table 5. The Doctrine of Double Effect

The nature of the act must be good or morally neutral.
The intent must be a good effect, but a bad effect may be predicted and permitted.
The bad effect must not be the means to the good effect.
The good effect must outweigh the bad effect.

Data from Enck RE. Drug-induced terminal sedation for symptom control. Am J Hosp Palliat Care 1991;8:3–5.

CONCLUSION

Palliative sedation is an option for the relief of refractory symptoms in dying patients. The frequency of the practice is not well established, but with an emerging consensus on its definition and the publication of clinical practice guidelines, more studies to define the epidemiology and management of palliative sedation can be expected. Sedative medications, such as benzodiazepines and barbiturates in continuous drips, can be used in a patient with any combination of refractory physical, psychologic, or spiritual distress. Consulting with palliative medicine physicians and proper documentation of attempted symptom relief and conversations with the patient or patient's family are ways to reduce the risk of misinterpretation and miscommunication. Palliative sedation is available but should be chosen as a therapeutic option of last resort, after all other feasible interventions have been exhausted. **HP**

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