



Palliative Sedation

When Suffering Is Intractable at End of Life

Peg Nelson Bander, MSN, NP, ACHPN, FPCN

Palliative sedation at the end of life is a necessary option for patients who have intractable symptoms and are suffering when other palliative interventions have been ineffective. Although recognized in palliative care as an ethically sound and legally sanctioned practice, some nurses continue to express concern that death is being hastened. The intent of this article is to provide clarity to the practice of palliative sedation at end of life.

KEY WORDS

double effect, ethics, euthanasia, palliative sedation

Although most patients at end of life exhibit suffering that can be controlled to a tolerable level, there are situations when physical and/or psychological distress, even with expert palliative care, precludes any hope for a peaceful death. Palliative sedation is a treatment that may be offered as a last resort to dying patients, when all other treatments of suffering have failed. Review of palliative sedation literature and practice indicates a lack of consensus of practice methods, definitions, and significant expressions of ethical concern and conflict by practitioners on the moral appropriateness of its use. The key ethical concern being as follows: Is palliative sedation actually euthanasia and does it hasten death? This article will present a case that demonstrates the use of palliative sedation and one nurse's conflicts with participating with the practice. A review of the current and seminal literature regarding the practice of palliative sedation, including the ethical principles that guide its use, will be discussed. Moreover, suggested guidelines for nurses and healthcare teams to follow when considering and implementing palliative sedation will be provided.

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LITERATURE REVIEW

The documented practice of palliative sedation goes back only 25 years. First described by Enck¹ in 1991 as drug-induced terminal sedation for difficult to control symptoms, the understanding and review of the practice of palliative sedation can be initially separated into 2 groups. In the first 10 years, most articles discussing palliative sedation focused on differentiating the practice from euthanasia. This issue will be addressed in the ethics section of this article. Once the practice was deemed ethically defensible and legally sanctioned, the second decade after its introduction saw the development and publication of numerous expert-driven, consensus-based guidelines established for its practice. However, lingering challenges and concerns remain including significant variations in practice that lacked consensus. These practice areas were identified by Henry² as inconsistent terminology, the use of palliative sedation for nonphysical suffering, the ongoing experience of suffering by family and nursing during the implementation of sedation, and the continued concern that palliative sedation hastened death. Over the past 5 years, there has been some movement and clarity regarding these issues.

TERMINOLOGY

Palliative sedation has also been called terminal sedation, sedation in patients with intractable symptoms, sedation for intractable distress in the imminently dying, end-of-life sedation, total sedation, palliative sedation therapy, controlled sedation, and proportionate sedation.³ Since 2010, there has been more consistent use of the term palliative sedation. The Hospice and Palliative Nurses Association, in its position statement supporting palliative sedation, specifically uses the term palliative sedation as the words "...more accurately reflect the intent and application of its use—to palliate the patient's experience of symptoms rather than to cause or hasten the patient's death."⁴ Although there is no universally agreed-upon term for palliative sedation, the practice is commonly understood to be the monitored use of nonopioid medications to create controlled sedation to the point of unconsciousness in a patient very near death, with the purpose of relieving symptoms that cannot be controlled using other measures.⁵

The type of refractory patient suffering (physical versus existential) for which palliative sedation may be indicated



is another consideration to explore. Common physical reasons for the use of palliative sedation include delirium, dyspnea, pain, and vomiting. The use of palliative sedation for nonphysical symptoms continues to be controversial. The concept of existential suffering near end of life, also termed spiritual distress, is common. A sense of purpose, freedom, and authenticity in life are fundamental existential aspects of a person. The term existential suffering or spiritual distress typically relates to a loss of ability to find a sense of hope, meaning, and purpose in one's life or explained as a loss of dignity, fear of death, fear of being a burden, or profound loneliness.⁶⁻⁸ For some patients with terminal disease, existential suffering can be intolerable. For most patients, however, there is a blend of physical, psychiatric, and existential suffering intertwined with end of life.

When Should Palliative Sedation Be Considered?

Ensuring that treatments for all types of suffering are exhausted is the first step when considering the use of palliative sedation. The American Medical Association and the Veterans Association Ethics Committees both recommend *against* the use of palliative sedation for nonphysical symptoms.^{9,10} Others argue that it is not about the cause of the suffering, but it is the severity of the distress and the proximity to death that should be the deciding factors on whether palliative sedation be considered. In the Netherlands, where the use of palliative sedation is more accepted for existential suffering, approximately 26% of patients had documented refractory existential distress.¹¹

Respite Sedation

Especially when existential suffering exists, a short-term trial of palliative sedation (called respite sedation) seems prudent and practical. Respite sedation is typically 24 to 48 hours in duration and has been found to help reduce suffering and a means to evaluate the benefit of palliative sedation. When respite sedation was used, some patients were found to be able to break the cycle of distress and anxiety and, in the end, did not opt for further palliative sedation.¹² In practice within the United States, some clinicians and protocols limit palliative sedation to only patients with severe physical symptoms and others include existential and psychological distress. Critical to both practices when dealing with severe suffering at end of life is to assess and aggressively treat all physical, psychiatric, and spiritual/existential distress.

How Do Families and Nurses View/Experience Palliative Sedation?

Concern has been raised about the distress experienced by families and nursing during and after the use of palliative sedation. Although families, in general, report their loved one experienced a good death associated with palliative sedation, many family members also report that its

use caused them personal distress.¹³⁻¹⁵ Most commonly, families worried that the sedation actually shortened their loved ones' life, or they were conflicted about whether they should have chosen an alternative method to assist their family member. No significant studies of nursing perspectives on the use of palliative sedation in United States have been done, but European literature reflects not only an acceptance of the use of palliative sedation by nursing but also the burdens and distress at times during the implementation of the practice. Of note, when protocols, training, and supportive teams were in place, nursing found the burdens much less.¹⁶

In 2015, a Cochrane review looked at the evidence of benefit of palliative sedation and survival in the last days of life.¹⁶ A total of 14 studies were included, and there was no statistically significant difference in survival time from admission to death in 93% of the sedated and nonsedated groups. There was also no evidence that palliative sedation led to respiratory depression. Although this would suggest that palliative sedation does not ultimately hasten death, the reviewers did write that this evidence comes from low-quality studies so should be interpreted with caution. This leads to the continued concern some practitioners have with the practice.

In Summary

Over the past 25 years, there has been significant discussion in the literature regarding palliative sedation, and although progress has been made, there continues to be a lack of consensus about guidelines and protocols. The lack of consensus among experts demonstrates that even experienced palliative clinicians may be uncomfortable with palliative sedation.

THE CASE

Jacques, a widower, was 73 years old and had been fighting stage 4 non-small cell lung cancer for the last 10 months. He was originally from Brussels, Belgium, and had come to New York as a small boy. He smoked 1 to 2 packs of cigarettes for more than 40 years. He also had advanced chronic obstructive pulmonary disease, was on oxygen at 3 L/nasal cannula, and had lost more than 85 lb in the last year. Always tall at more than 6 ft, 2 in, he now looked like a skeleton. His lung cancer at time of diagnosis was also found in his femur and liver. Early in his treatment, Jacques was feeling better and more active. But over the past 2 months, in spite of palliative chemotherapy, his cancer had progressed to multiple bones, and he now had significant pleural effusions. He had an intrapleural catheter in his right chest, and his functional status had declined drastically. He now spent most of his time in bed or a chair and was unable to do any of activities of daily living. Jacques' oncologist met with Jacques and his grandson Aiden and his grandson's wife Eva, who were his



primary caregivers and lived with him in his home. Jacques, although frail, was alert and oriented and had insight into his medical condition. The doctor discussed with Jacques his medical problems and end-of-life situation. Hospice was recommended. Although everyone was sad, this was not unexpected. "I knew this was coming," Jacques remarked. Arrangements were made for the hospice team to meet with Jacques and his family at home the next day.

Nona had been a nurse for 8 years and had worked in hospice for the past 2 years. She was assigned to Jacques as his primary registered nurse and went out to do the admission in his home. Jacques' physical symptoms included a nagging cough, moderate shortness of breath, fatigue, and mild lower back pain. He was very weak and used a walker to ambulate. She arranged for him to have a commode chair and hospital bed and discussed management of his physical symptoms with the advanced practice registered nurse who was his attending clinician with hospice. Jacques reported anxiety that worsened when his shortness of breath worsened, and he also was having trouble sleeping because of the persistent cough. Initially, over the first few weeks of hospice care, Jacques' symptoms improved, and he reported increased energy, better sleep, and improved spirits. But after 3 weeks, Jacques' coughing became continuous. In spite of multiple oral and inhaled medications and an additional intrapleural catheter placement on the left, Jacques coughed so hard 1 night he fractured 3 ribs and was in excruciating pain. His pain and persistent cough were unable to be controlled at home, and he was admitted to the hospital for symptom control. He was no longer eating and only taking sips of fluids. A consult to the palliative care team and anesthesia was placed to assist control his distress.

Nona, his hospice nurse, also visited at the hospital and worked with the patient and his family. Attempts to relieve his pain and cough included a nerve block and intravenous pain and cough medications. His cough and pain continued, however, causing severe distress. Jacques begged for relief. He begged for death. He and his family were suffering terribly. The palliative care team discussed Jacques' case at their interdisciplinary team meeting. The use of palliative sedation was suggested. Nona had never seen this type of sedation used, and after listening to the protocol, she was very concerned. "It seems like we are killing him, and not just treating his symptoms. I don't think I can participate in this. To me, this is euthanasia." Even though the team leaders explained that the intent of the palliative sedation was to stop his suffering, that he was close to death, that he had likely only days to live, that this treatment would enable a peaceful death rather than dying in agony, and that the intent was not to hasten his death but to allow a natural death with comfort, Nona was not convinced. Despite several discussions, Nona could not find it in her moral code to participate in this approach to relieving intractable

suffering at end of life. Another hospice nurse Maggie, took over the care of the patient for Nona.

The chaplain and social worker assessed Jacques and his family for spiritual and existential distress. A psychiatrist also assessed him for anxiety, depression, delirium, and other psychiatric illness. The team identified that Jacques' distress was primarily from the severe pain and cough. He remained alert and oriented and in control of his own decision making. He was near death, likely only days away, and the hospice/palliative team discussed the prospect of palliative sedation with him and his family. Everyone was supportive. Jacques said, "I've lived a good life; I've fought hard, but I cannot take this misery any longer." His family also said that watching him suffer like this was unbearable. Jacques had already made himself a Do Not Attempt Resuscitation, and his goal of his care was comfort and a peaceful death. Sedation was planned for the next morning. Jacques and his family met with their own pastor and spent the night together. No one slept, but they shared their love, their sadness, and the effect that each had on one another. In the morning, an intravenous drip of Diprivan was initiated, and within 10 minutes, Jacques was sleeping peacefully. His family stayed by his side, and he died 2 days later.

LEGAL, ETHICAL, AND MORAL IMPLICATIONS

Many perceived ethical and moral conflicts occur surrounding the use of palliative sedation. Importantly, cultural, religious, and ethnic values weigh in on each person's understanding and ability to endorse and participate in this approach to relieving intractable symptoms and suffering. There can be misunderstanding and confusion about its intent and the differences between palliative sedation, euthanasia, and assisted suicide. Legal cases that set a precedent and support the use of palliative sedation for intractable suffering at end of life are important for nurses and other team members who care for the dying to be aware of.

BACK TO THE CASE

The Need for Definitions

Nona felt that palliative sedation was a type of murder or assisted suicide. Others believe it is a veiled form of euthanasia (remember opinions are not facts). Definitions provided by Nelson⁵ clarify the difference between palliative sedation, euthanasia, and assisted suicide:

Palliative sedation is the controlled induction of sedation to the point of unconsciousness in a dying patient to relieve otherwise uncontrolled suffering. The intent of this therapy is to control intolerable symptoms that have not been controlled by other approaches to palliation. This therapy is typically continued until the patient dies a natural



death. *Euthanasia* is the act of bringing about the death of a person at his request. In euthanasia, the intent is to relieve suffering through death. Euthanasia is legal in some European countries but not in any states in America. *Voluntary active euthanasia* is when a physician administers a lethal dose of medication at the request of a competent patient; the intent is to relieve suffering through death. Physician-assisted suicide (PAS) also known as physician aid in dying (PAD) is legal in some states within the United States. The PAS/PAD is when a physician prescribes a lethal dose of medication at the request of a competent terminally ill patient and within specific guidelines that can be self-administered by the patient at a time of his choosing with the intent of death. The important nuance in these definitions is the intention of the act. Palliative sedation's intent is to relieve suffering through sedation and not to relieve suffering through death. The intent of both voluntary active euthanasia and PAS/PAD is also to relieve suffering but through causing death. The American Nurses Association (ANA) position statement on Nurses' Roles and Responsibilities in Providing Care and Support at the End of Life states that "While nurses should make every effort to provide aggressive symptom management at the end of life, it is never ethically permissible for a nurse to act by omission or commission, including but not limited to medication administration, with the intention of ending a patient's life."¹⁷

LEGAL PRECEDENT

Several important legal cases over the years have set the legal precedent and support for the use of palliative sedation at end of life. Supreme Court Justice O'Connor in decisions *Vacco v. Quill*¹⁸ and *Washington v. Gluckberg*¹⁹ in 1997 stated that "a patient who is suffering from a terminal illness and who is experiencing great pain has no legal barriers to obtaining medication, from qualified physicians, to alleviate that suffering, even to the point of causing unconsciousness and hastening death."²⁰ Justice O'Connor went on to say very eloquently what end of life means for people. "Death will be different for each of us. For many, the last days will be spent in physical pain and perhaps the despair that accompanies physical deterioration and a loss of control of basic bodily and mental functions. Some will seek medication to alleviate that pain and other symptoms."

Palliative sedation is not only a legal act; it is grounded in basic ethical precepts including dignity, autonomy, fidelity, beneficence, nonmaleficence, and the principle of double effect. A fundamental principle that underlies all nursing practice is respect for the inherent worth, dignity, and human rights of every individual. The ANA position statement on Risk and Responsibility in Providing Nursing Care²¹ states that "The ANA believes that nurses are obligated to care for patients in a nondiscriminatory manner, with respect for all individuals."

By reducing suffering at the end of life, palliative sedation frees a patient from severe distress and preserves the dignity of the person. *Autonomy*, sometimes called self-determination, is the right of a capacitated individual to decide for himself/herself a course of action based on that person's goals and values. Within the United States, autonomy is both a strongly held legal and ethical core belief. Autonomy is derived from the ethical principle of respect for persons. Informed consent is an important aspect of supporting autonomy. As with any informed consent process before any medical intervention, information is necessary, so that the patient or surrogate can make an informed choice regarding palliative sedation including benefits and risks. The ethical imperative of *fidelity* is our commitment in healthcare to keep our promises to patients. At end of life, our commitment to nonabandonment of the patient especially at the time of greatest need is paramount. Doing good or *beneficence* is the duty to care in a way that benefits our patients. The management of distressing symptoms is a way we demonstrate this. *Nonmaleficence* dictates that we do not cause harm to our patients through acts of omission or commission. Inadequate treatment of pain and suffering at end of life, when we have the means to do so, is an example of maleficence.

BACK TO THE CASE

Nona felt she would be harming Jacques, hastening his death, by participating in palliative sedation. She felt trapped in a tension between the principles of beneficence and nonmaleficence. Some clinicians have used nonmaleficence as a moral argument against the use of palliative sedation. This is despite the evidence that in most cases palliative sedation when used appropriately does not hasten death.¹⁶ Allowing suffering to continue, when we have the capability to create comfort, violates the principle of nonmaleficence. By creating and following institutional guidelines and protocols for palliative sedation, which include appropriate patient selection and use and monitoring of medications, we reduce potential for harm.

Another ethics argument that supports the use of palliative sedation is the principle of double effect. In the principle of double effect, there are both good and bad potential outcomes of an action that can be foreseen, but the action is considered ethical/moral if the intent of the action is good. For example, with palliative sedation, the goal/intent of sedation is to relieve severe suffering (this is morally good). The potential bad effect is foreseen (to hasten death or cause some complication), but the bad effect (potentially causing complication or hastening death) is not the means or the intent of the action so the use of palliative sedation is morally permissible.

The Hospice and Palliative Nursing Association, the American Academy of Hospice and Palliative Medicine,



TABLE Protocol for Palliative Sedation

The Key to Appropriate Use of Palliative Sedation Is to Ensure That Best Practice and Ethical Norms Are Available to Guide Its Implementation. The Following Are the Key Elements for Hospices and Other Healthcare Institutions to Include Within Palliative Sedation Protocols and Guidelines⁵

A. Patient condition meets criteria for palliative sedation
a. Interdisciplinary assessment of the patient includes primary nursing, medical, social work, and chaplaincy providers
b. The patient must be imminently dying
i. Life expectancy is hours to days
ii. A DNAR order is in place
c. Severe intolerable symptoms refractory to treatment
i. Aggressive palliative care short of sedation fails to provide relief
ii. Additional invasive/noninvasive treatment unable to provide relief
iii. Additional therapies are associated with excessive/unacceptable morbidity or are unlikely to provide relief with a reasonable time frame
iv. All palliative treatments must be exhausted, including treatment for depression, delirium, anxiety, and any other contributing psychiatric illnesses
v. Expert consultations from other specialties (ie, psychiatry for delirium, pain service for pain syndromes, pulmonology for respiratory issues offer no further alternatives)
vi. Completion of a psychological assessment by a skilled clinician
vii. Completion of a spiritual assessment by a skilled clinician or clergy
B. Clinician/team member competence, involvement and care
a. Consultation and collaboration
i. Primary team should consult a palliative care expert (physician or APRN)
ii. Attending of record (MD, DO, or NP) should consult appropriate specialists to discuss all invasive and noninvasive options available to manage target symptom(s)
iii. As appropriate to address additional patient needs/distress, there is further assessment by the palliative care IDT of the family and the patient to offer support
iv. Collaboration between primary care team, hospice (as appropriate), and palliative care team members with patient and family and direct care providers such as registered nurses and nursing assistants
b. Team education and support
i. All healthcare clinicians involved in the patient's care should be educated regarding process and ethics of palliative sedation
ii. Team discussion to review the process and policy for enactment
iii. Allowance for conscientious objection and process for transferring care to another provider if staff member finds practice against his moral framework
iv. Process for ongoing care and support of healthcare team and opportunity for debriefing and sharing after the death and/or palliative sedation experience
C. Informed consent and decision making with the patient and family
a. Education, information, and discussion regarding the elements of palliative sedation, including outcomes, the procedure risks, and potential benefit including clear understanding of the death to occur likely in hours to days

(continues)

**TABLE Protocol for Palliative Sedation, Continued**

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b. Encouragement of family in decision making
c. Discussion of impending death is included and planning for death experience includes cultural, religious, and personal wishes
d. Cessation of artificial nutrition and hydration is discussed and typically done except for cases when respite sedation is provided
e. Informed consent should be obtained from the patient or surrogate decision maker (written or verbal based on hospital policy)
f. Detailed documentation of the content of the consent discussion within medical record
D. Care of the family
a. Assess the distress of the family and provide ongoing support
b. Assurance of nonabandonment
c. Active listening
d. Conveyance of concern and caring for patient and family
e. Ongoing truthful compassionate communication regarding patient status and meanings behind medical information
E. Selection of medication for palliative sedation
a. Analgesics are not a primary sedative drug. They are continued as a symptom treatment if already in place and delivered alongside other sedatives for sedation to unconsciousness
b. Consideration for the use of respite sedation especially in patients with existential or spiritual distress as a primary cause of suffering
c. Medications used to sedate patient are based on
• the symptom to be treated
• current medications in use or successfully used in the past
• medication efficacy, potential for adverse effect
• medication access (IV, PO, PR, SQ)
d. Suggested sedatives and initial dosing
• Usual medications include barbiturates and anesthetics
• Propofol (Diprivan): Initial bolus 10-20 mg and drip of 5-10 mg/h with titrations of increments of 10-20 mg/h every 10 min as needed until control of symptoms is achieved
• Thiopental: Initial bolus 5-7 mg/kg per hour IV bolus and the 20-80 mg/h as a drip. Titrate to control of symptoms
• Pentobarbital: 1-3 mg/kg IV bolus and drip at 1 mg/kg per hour and titrate until control of symptoms
• Midazolam: 2-5 mg IV bolus (can be SC) with a drip at 1 mg/h and titrate to control symptoms
• Precedex (Dexmedetomidine): Drip is initiated with initial bolus and typical dosing is within the range of 0.2-0.7 mcg/kg per hour
F. Care of the patient
a. Maintain hygiene, dignity, skin care, and elimination
b. Attention to the patients culture and religion and rituals
c. Creation of comfortable environment that supports the patient's family

(continues)



TABLE Protocol for Palliative Sedation, Continued

The Key to Appropriate Use of Palliative Sedation Is to Ensure That Best Practice and Ethical Norms Are Available to Guide Its Implementation. The Following Are the Key Elements for Hospices and Other Healthcare Institutions to Include Within Palliative Sedation Protocols and Guidelines⁵

d. Creating special memories by helping families at the bedside take pictures, make hand casts, or use other methods that will help in the transition

e. Bereavement care during the dying process and post death

Abbreviations: DNAR, do not attempt resuscitation; APRN, advanced practice registered nurse; MD, doctor of medicine; DO, doctor of osteopathic medicine; NP, nurse practitioner; IDT, interdisciplinary team; IV, intravenous; PO, oral; PR, per rectum; SQ, subcutaneous.

the National Hospice and Palliative Care Organization, and other professional organizations endorse palliative sedation for the relief of intractable symptoms and suffering at end of life.^{4,22,23} However, some within healthcare and the lay community continue to find its use to be inconsistent with their values, culture, religious views, or moral code. The Code of Ethics for Nurses supports that if a nurse deems a particular decision or action to be morally objectionable the nurse is justified in refusing to participate on moral grounds.²⁴ If a nurse has a conscientious objection to being involved in the care of a patient under palliative sedation, the nurse has the option of transferring the care of the patient to another nurse so that the patient is not abandoned and is provided with the needed care.

SUMMARY

The intent of palliative sedation at end of life is to create peace and comfort for a patient who is experiencing intolerable suffering and other approaches to palliation have been ineffective. This therapy is both ethical and legally sanctioned. Its use should be guided by evidence-based guidelines or protocols (Table 1), involve patient or agent/surrogate consent, and be delivered by an interdisciplinary team. Palliative sedation is a therapy of last resort and should be available and offered to patients when all other palliative measures to relieve suffering have failed.

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