

THE ETHICS OF PALLIATIVE SEDATION

*A Report by the National Ethics Committee
of the Veterans Health Administration*

March 2006



*National Center for Ethics in Health Care
Veterans Health Administration
Department of Veterans Affairs*

Founded in 1986, the National Ethics Committee (NEC) of the Veterans Health Administration (VHA) is an interdisciplinary group authorized by the Under Secretary for Health through the National Center for Ethics in Health Care. The NEC produces reports on timely topics that are of significant concern to practicing health care professionals. Each report describes an ethical issue, summarizes its historical context, discusses its relevance to VHA, reviews current controversies, and outlines practical recommendations. Previous reports have been useful to VHA professionals as resources for educational programs, guides for patient care practices, and catalysts for health policy reform. Scholarly yet practical, these reports are intended to heighten awareness of ethical issues and to improve the quality of health care, both within and beyond VHA.

Committee Members: Michael D. Cantor, MD, JD (Chair); Lawrence Biro, EdD; Susan Bowers, MBA; Jeanette Chirico-Post, MD; Sharon P. Douglas, MD; Gwendolyn Gillespie, MSN, RN, APN; Kathleen A. Heaphy, JD; Ware Kuschner, MD; Michael McCoy; Richard Mularski, MD, MSHS; Heather Ohrt, MD; Judy Ozuna, ARNP, MN, CNRN; Peter Poon, JD, MA; Cathy Rick, RN, CNAA, FACHE; Randy Taylor, PhD, MBA, CHE.

Ex Officio: Ellen Fox, MD

Consultant to the Committee: Michael J. O'Rourke

Staff to the Committee: Bette-Jane Crigger, PhD; Michael Ford, JD

Director, National Center for Ethics in Health Care: Ellen Fox, MD

The National Ethics Committee is grateful to the following individuals, who contributed their expertise in reviewing drafts of this report:

Robert M. Arnold, MD, University of Pittsburgh, Section of Palliative care and Medical Ethics
Amos Bailey, MD, Palliative Care Director, Birmingham VAMC
Matthew J. Bair, MD, Indianapolis VAMC
Rigney Cunningham, Executive Director, Hospice & Palliative Care Federation of Massachusetts
Christine Elnitsky, member, VA National Pain Management Strategy Coordinating Committee
James Hallenbeck, MD, Director of Palliative Care Services, VA Palo Alto Health Care System
and Assistant Professor of Medicine, Stanford University School of Medicine
Stan Hall, FNP, Boise VAMC
George F. Kelly, MA, VA NJ Health Care System
Robert D. Kerns, PhD, National Program Director for Pain Management, VHA
Anna Lythgoe, VHA Office of Quality and Performance
Hugh Maddry, Director, VHA National Chaplain Center
Kenneth Rosenfeld, MD, Director, Veterans Integrated Palliative (VIP) Program, VA Greater
Los Angeles Healthcare System
Paul Rousseau, MD, GEC Administrator, Phoenix VAMC
Scott T. Shreve, MD, National Director, Hospice and Palliative Care
James Tulskey, MD, Ethics Committee Co-Chair, Durham VAMC
Joan Van Riper, Director, VHA National Patient Advocacy Program
David Weissman, MD, Palliative Care Center, Medical College of Wisconsin

Executive Summary

Many patients nearing the end of life reach a point at which the goals of care change from an emphasis on prolonging life and optimizing function to maximizing the quality of remaining life, and palliative care becomes a priority. However, for some patients even high quality aggressive palliative care fails to provide relief. For patients suffering from severe pain, dyspnea, vomiting, or other intrusive symptoms that prove refractory to treatment, there is a consensus that palliative sedation is an appropriate intervention of last resort.

In this report, VHA's National Ethics Committee (NEC) examines what is meant by palliative sedation, explores ethical concerns about the practice, and reviews the emerging professional consensus regarding the use of palliative sedation for managing severe, refractory symptoms at the end of life. The report recommends that VA adopt policy that:

- (1) Permits the administration of palliative sedation (by definition, as a last resort) only:
 - (a) when severe pain or other clinical symptoms (e.g., dyspnea, nausea and vomiting, agitated delirium) is/are not ameliorated by aggressive symptom-specific interventions that are tolerable to the patient;
 - (b) for patients who have entered the final stages of the dying process and who have a DNR order;
 - (c) with the signed informed consent of the patient, or surrogate if the patient lacks decision-making capacity, as required by VA policy for treatments or procedures involving general anesthesia.

- (2) Establishes safeguards to protect patients' interests and assure consistent, high quality care by:
 - (a) providing for consultation with experts in palliative medicine, psychiatry or clinical psychology, and spiritual care as appropriate in the decision-making process;
 - (b) clarifying with the patient and/or surrogate the plan of care regarding concurrent life-sustaining treatment, regular assessment of the patient's clinical status and ongoing eligibility for palliative sedation, and the practitioner's obligation to discontinue deep sedation in the event the patient's status improves;
 - (c) assuring the participation of a health care professional with appropriate expertise in palliative care and the administration of palliative sedation;
 - (d) assuring that the patient continues to receive appropriate care and hygiene;
 - (e) monitoring sedation to assure adequate and continuous unconsciousness while avoiding inappropriate or unnecessary untoward drug effects;
 - (f) documenting the rationale for palliative sedation and the informed consent conversation appropriately in the patient's health record; and
 - (g) establishing clear procedures for resolving disagreements about treatment plans or specific treatment decisions, including ethics consultation when appropriate.

Introduction

For most patients nearing the end of life, there comes a point at which the goals of care evolve from an emphasis on prolonging life and optimizing function to maximizing the quality of remaining life, and palliative care becomes the priority. Providing adequate relief of symptoms for dying patients is one of the hallmarks of good palliative care.¹ Yet for some patients, even aggressive, high quality palliative care fails to provide relief. For patients who suffer severe pain, dyspnea, vomiting, or other symptoms that prove refractory to treatment, there is consensus that deep sedation—so called “palliative sedation”—is an appropriate intervention of last resort.²⁻⁵ The National Hospice and Palliative Care Organization⁶ and the American Academy of Hospice and Palliative Medicine⁷ support the use of sedation to treat otherwise unrelievable suffering at the end of life, and the practice has been endorsed by the End-of-Life Care Consensus Panel of the American College of Physicians–American Society of Internal Medicine,⁸ and the American Medical Association.⁹

This report by VHA’s National Ethics Committee (NEC) examines what is meant by palliative sedation, explores ethical concerns about the practice, reviews the emerging professional consensus regarding the use of palliative sedation for managing severe, refractory symptoms at the end of life, and offers recommendations for ethical practice within VHA.

WHAT DO WE MEAN BY “PALLIATIVE SEDATION”?

The literature describes several uses of sedation as a palliative intervention at the end of life, variously referred to as “palliative” or “terminal” sedation.^{1, 3,8,10-13} Broadly, the practice involves “sedating a patient to the point of unconsciousness to relieve one or more symptoms that are intractable and unrelieved despite aggressive symptom-specific treatments, and maintaining that condition until the patient dies.”¹⁴ The intent, thus, is to provide symptom relief for a dying patient when all other efforts have failed.

Palliative sedation is distinct from sedation that normally accompanies therapeutic interventions, such as intubation or treatment of severe burns, when recovery is expected or more likely to occur.¹⁵⁻¹⁷ Intentionally sedating the patient as a palliative intervention is also distinct from the unintended and variable sedative effects of medications administered for pain relief.^{18,19} Some scholars and practitioners further distinguish palliative sedation from “respite sedation” for terminally ill patients; that is, from time-limited therapy (e.g., 24–48 hours) offered in the hope that temporary sedation will break a cycle of pain, anxiety, and distress.¹⁷

For purposes of this analysis, the National Ethics Committee defines 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.

There is broad professional agreement that palliative sedation is a clinically and ethically appropriate response when patients who are near death suffer severe, unremitting symptoms.^{7,8,10,11,19-22} The following algorithm has been proposed to help clinicians determine when a symptom is truly refractory: (1) Are further interventions capable of providing further relief? (2) Is the anticipated acute or chronic morbidity of the intervention tolerable to the patient? (3) Are the interventions likely to provide relief within a tolerable time frame?^{15,23} If the answer to any of these three questions is “no,” then these are refractory symptoms for which palliative sedation may be considered.

Palliative sedation is provided for a wide range of symptoms. One recent review of published studies, for example, found that the primary indications for this intervention included pain, nausea

¹ Other terms include “total sedation”^{6,59} and “sedation of the imminently dying.”³⁷

and vomiting, shortness of breath, and agitated delirium.^{13,20,24–26} Other indications for which palliative sedation has been reported include urinary retention due to clot formation,²⁴ gastrointestinal pain and uncontrolled bleeding,¹³ and myoclonus.²⁷ Many also support palliative sedation to relieve severe psychological distress in a dying patient,^{15,20,28} with the important caveat that potentially treatable mental health conditions first be ruled out.²⁹

ETHICAL CONCERNS ABOUT PALLIATIVE SEDATION

Ethical debate about palliative sedation has been framed largely in terms of five key questions: (1) Is palliative sedation ethically different from physician-assisted suicide and euthanasia? (2) Is palliative sedation ever ethically appropriate for patients who are not imminently dying? (3) Should willingness to forgo life-sustaining treatment be a condition for administering/receiving palliative sedation? (4) Is palliative sedation an ethically appropriate response to “existential” suffering? And (5) May palliative sedation be provided to patients who lack decision-making capacity?

1. Is Palliative Sedation Different from Physician-Assisted Suicide and Euthanasia? Palliative sedation has been widely discussed in the context of debates about physician-assisted suicide and euthanasia.^{11,30,31} Indeed, palliative sedation has been proposed as an ethically acceptable alternative to physician aid in dying.^{10,11} Yet despite considerable attention to these questions over the past decade, many clinicians remain uncertain or confused about the ethical differences among these practices.²⁷

Although debate continues in some quarters, the dominant view in the professional medical and bioethics communities holds that palliative sedation is ethically different from physician-assisted suicide or euthanasia. These analyses focus on intention and proportionality.^{8,10,11,31,32} With respect to intention, in both physician-assisted suicide and euthanasia the primary intention is to cause the patient’s death; the patient’s suffering ends as a result. In contrast, in palliative sedation the primary intention is to relieve the patient’s suffering; death occurs as a result of the underlying disease process. (Note that because death occurs as a result of the disease process, palliative sedation shares a critical feature with established ethically accepted practice of forgoing life-sustaining treatment.) Medication is used only in sufficient doses to achieve unconsciousness (not a lethal dose).¹⁰ The limited evidence currently available suggests that deep sedation is unlikely to hasten death.^{19,20,33,34} In response to concerns that it is difficult to assess practitioners’ intentions objectively,³⁵ it has been argued that those intentions can be evaluated indirectly in a general way—e.g., by observing practitioners’ choice and usage of sedating medications.⁴

Proportionality is a second ethically significant factor in distinguishing palliative sedation from physician-assisted suicide and euthanasia. In medicine, the principle of proportionality requires that “the risk of causing harm must bear a direct relationship to the danger and immediacy of the patient’s clinical situation and the expected benefit of the intervention.”¹¹ Practitioners are permitted to perform, and patients to undergo, treatments and procedures that carry grave risks when there are commensurate benefits to be gained. Think of the example of surgery for a patient who is seriously injured in a car accident: Administering general anesthesia carries a foreseeable risk of death. Yet the good intended—for example, saving the patient’s leg or minimizing brain damage—is usually held to be significant enough to justify taking a substantial risk to obtain it. In palliative sedation, although the means—deep, continuous sedation for a dying patient—are grave, they are proportional to the goal to be achieved, relieving severe, unremitting suffering when all other interventions acceptable to the patient have failed.^{8,11,15,36,37}

The distinction between palliative sedation and either physician-assisted suicide or euthanasia recognized in the emerging medical and ethical consensus is also supported in case law. In its 1997 decisions in *Vacco v. Quill* and *Washington v. Glucksberg*,³⁸ two cases that dealt with physician-assisted suicide, the U.S. Supreme Court seemed to distinguish palliative sedation from assisted suicide as legally acceptable practice.^{21,39} The Court did not explicitly address palliative sedation as such, but did indicate strong support for aggressive symptom relief for dying patients, even to the point of rendering the patient unconscious.

The Committee concludes that there is a meaningful difference between palliative sedation and physician-assisted suicide or euthanasia.

2. Is Palliative Sedation Ever Ethically Appropriate for Patients Who Are Not Imminently Dying? The professional community is also divided about whether palliative sedation is ethically appropriate for a patient who experiences intolerable, irremediable suffering but who is not imminently dying. If palliative sedation is an ethically appropriate response to severe, intractable suffering, the argument goes, why should it be available only to patients who are on the verge of death? To withhold palliative sedation from patients whose symptoms are severe and refractory to aggressive care solely because they are not expected to die very soon, or because their condition makes it extremely difficult to predict likely time to death with any confidence, imposes an arbitrary constraint and condemns these individuals to endure unrelieved suffering for a potentially long period of time.^{6,8,30}

We recognize the ethical salience of this position. However, in our judgment, more compelling concerns are raised by the prospect of permitting palliative sedation for a patient who is expected to survive for months or years. Sedating a patient to unconsciousness carries significant risks, and palliative sedation is understood to be literally an intervention of *last* resort at the end of life.

Allowing palliative sedation when the patient can reasonably be expected to live for months (or longer) risks eroding the distinction between palliative sedation and physician-assisted suicide or euthanasia. Sedating such a patient in order to relieve suffering while respecting his or her right to forgo artificially administered nutrition and hydration or other indicated life-sustaining treatment will directly and predictably shorten the patient's life, a result clearly contrary to the goal of palliative sedation.⁴⁰

Providing palliative sedation to patients who are not imminently dying also raises slippery slope concerns. Palliative sedation is generally considered appropriate only for patients who are terminally ill—if not at the threshold of imminent death, at what other point in the trajectory of terminal illness can we draw a sufficiently bright line to distinguish when palliative sedation is and when it is not ethically permissible? Moreover, accepting “terminally ill” alone as a sufficient criterion for palliative sedation instead of the more restrictive “imminently dying” may increase the risk that the practice would some day be extended to individuals who are not terminally ill.⁴¹

Furthermore, intentionally sedating a patient and maintaining continuous deep sedation while providing life-sustaining treatment for an indefinite, but possibly prolonged span poses its own challenges. Such scenarios are likely to be emotionally distressing for the patient's intimates—and indeed, for staff.⁴²

A further concern, originally raised in reference to physician-assisted suicide,⁴³ may also be cogent with respect to palliative sedation for patients who are not imminently dying. *Viz.*, that deep sedation will come to be seen as an alternative to providing appropriate palliative care. High quality palliative care is an essential condition for ethical practice of palliative sedation.

We recognize that it is not possible to predict with certainty how long a patient will live. Patients with terminal cancer follow a relatively predictable course to death,⁴⁴ but even for these

patients physicians' predictions about the timing of death are not very accurate.^{45,46} For patients with other types of life-limiting illness—e.g. end-stage lung or heart disease—prognostication is even more challenging.⁴⁴ Ultimately, the determination that a patient has entered the final phase of dying rests not on precise predictions of survival, but on well-considered, informed professional judgment, which argues for the involvement of practitioners with appropriate expertise, including palliative care specialists, in decision making about palliative sedation.

The Committee concludes that it is ethically appropriate to restrict palliative sedation to patients who are imminently dying.

3. Should Willingness to Forgo Life-Sustaining Treatment Be a Condition for

Administering/Receiving Palliative Sedation? Professional consensus regarding best practice for palliative sedation clearly establishes that patients who do not have a do-not-resuscitate (DNR) order should not be considered appropriate candidates for palliative sedation.^{12,15,16,20,22,23,47–49} The Committee believes this is an appropriate standard consistent with the overall goals of palliative sedation. However, debate continues within the medical community about whether it is ethically appropriate to provide other life-sustaining interventions, such as ventilator support, dialysis, or artificially administered nutrition and hydration to patients who receive palliative sedation.^{30,31,40,49}

For the majority of patients who are appropriate candidates for palliative sedation, the question of life-sustaining treatment is not likely to arise. These are patients near death, for whom the overriding goal of care is no longer to optimize function or prolong survival but to provide comfort and symptom relief. Most such patients will already have stopped eating and drinking.^{19,33} As a practical matter, most patients who are candidates for palliative sedation will have already decided to forgo all life-sustaining interventions. When this is not the case, the decision to forgo life-sustaining treatment should be clearly distinguished from and made independently of the decision to provide palliative sedation.⁵⁰

However, some dying patients who are appropriate candidates for palliative sedation will want *both* palliative sedation *and* life-sustaining treatment. For these patients, the goal of care is twofold: to relieve suffering *and* to prolong life. Many cultural and religious traditions place high moral value on prolonging life and practitioners have a *prima facie* obligation to respect these views, an obligation that also resonates with core values of medicine as a profession.

Consensus in the professional community is that candidates for palliative sedation should have a DNR order. However, we find no compelling argument to limit other concurrent life-sustaining interventions (such as artificially administered nutrition and hydration or ventilator support) for patients who receive palliative sedation, so long as those interventions are clinically indicated. To require that a patient consent to forgo *all* life-sustaining treatments as a condition for receiving the only intervention that will relieve the patient's intolerable suffering—i.e., palliative sedation—seems to us ethically and professionally insupportable.

We recognize that views are divided on the question. Most members of the Committee would argue that first and foremost, continuing to provide life-sustaining treatment to a patient who receives palliative sedation and who wants life-sustaining treatment(s) other than CPR upholds the value of respect for patients as moral agents and autonomous decision makers. However, some members see it as unnecessarily prolonging dying, a view we realize others may share. We acknowledge that for both family members and health care professionals who hold this latter view, providing life-sustaining treatment concurrent with palliative sedation may create significant distress.

These considerations carry significant implications for decision making regarding palliative sedation. Practitioners have an obligation to describe as clearly as possible the likely clinical scenarios for a patient who is considering palliative sedation, and should work with patients and families to

establish a clear plan of care prior to initiating sedation. This should include discussion of what life-sustaining treatments will be withdrawn, continued, or initiated (if clinically indicated) after the patient has been sedated. This will help patients, their surrogates, other family members, and, indeed, the treatment team understand what is expected to happen once the patient has been sedated and better prepare them for the decisions that may need to be made when the patient is no longer conscious.

As potential sources of conflict, diverging views on the question of life-sustaining treatments for patients who receive palliative sedation also highlight the importance of assuring that appropriate mechanisms are in place to assist stakeholders in resolving disagreements if they arise, including ethics consultation.

The Committee concludes that willingness to forgo life-sustaining treatment should not be a condition for the administration of palliative sedation.

4. Is Palliative Sedation Ethically Appropriate When Suffering Is “Existential”? One of the most deeply contested questions about palliative sedation is whether the practice is ethically appropriate as a response to “existential suffering,” as distinct from pain or other clinically defined physical or psychiatric symptoms. The debate about existential suffering has evolved around three basic concerns: (1) the difficulty of clearly defining existential suffering and of distinguishing it clinically from treatable psychiatric conditions (e.g., depression); (2) whether relief of existential suffering represents a “proportionate” goal; and (3) whether relief of existential suffering as such is within goals of medicine, and thus whether providing a pharmacological intervention for such suffering is appropriate for health care professionals.

Distinguishing existential suffering from psychological distress. One difficulty is that there is no single, agreed on definition of existential suffering that is sufficiently clear and concrete to offer guidance in clinical contexts. “Making a diagnosis of suffering,” it has been argued, “differs from the usual diagnostic process that internists are familiar with because suffering is an affliction of the person, not the body.”⁵¹ The suffering experienced by patients near death may reflect concerns about a prolonged dying process, retaining control, the burden their dying imposes on others, and strengthening personal relationships.⁵¹

Moreover, it can be extremely difficult to draw bright lines among physical, psychological, and existential suffering.^{29,50} Psychological distress often contributes to pain, dyspnea, and other symptoms, for example, as well as the reverse. Nor is it always easy for practitioners to determine with confidence whether a patient’s distress represents a normal, “appropriate” reaction to the prospect of impending death or indicates the presence of a potentially treatable mental health condition.⁵² It is even more challenging to assess whether the patient’s distress reflects the kind of response to the irremediable losses imposed by illness and assaults to the sense of self that we would call existential suffering.

“Proportionality” and relief of existential suffering. A further concern can be framed as the following question: Is the goal of relieving severe, refractory existential suffering sufficiently grave or “proportionate” as to justify sedating the patient into unconsciousness for the time remaining to him or her? Some answer in the affirmative, arguing that existential suffering “can be just as distressful and refractory as physical suffering,”³⁶ but acknowledge that practitioners may find it difficult to consider palliative sedation when a patient’s existential suffering is not associated with significant physiological deterioration.^{29,47} Opponents of palliative sedation for existential suffering argue that permitting practitioners to make necessarily subjective judgments about the existential well-being of patients risks placing health care professionals and patients on a slippery slope at the bottom of which lies abuse of palliative sedation and danger to patients.³⁷

Relief of existential suffering and the goals of medicine. Undeniably, for some patients, suffering at the end of life cannot be attributed solely or primarily to refractory clinical symptoms.⁵³ But although relieving suffering is one of the core goals of medicine,^{51,54} questions have been raised about whether attempting to relieve existential suffering through a specifically clinical intervention, such as palliative sedation, is an appropriate activity for health care professionals.⁵⁵ Essentially the same concern has been raised with respect to physician-assisted suicide and euthanasia. As the ACP-ASIM noted in its position statement opposing physician-assisted suicide, “one can raise serious questions about whether medicine should arrogate to itself the task of alleviating all human suffering, even at the end of life.”⁵⁶

Despite these concerns, there is some degree of support for palliative sedation in response to existential suffering within the professional hospice and palliative care community in the United States. For example, the Hospice and Palliative Care Federation of Massachusetts has provided guidelines for providers, although it has not formally endorsed palliative sedation,⁴⁹ and the National Hospice and Palliative Care Organization has cautiously supported the practice in principle.⁶

These are challenging issues on which the Committee finds that as individuals we do not share a uniform perspective. This lack of consensus within the Committee itself recommends to us the wisdom of taking a conservative stance with respect to palliative sedation for existential suffering. Further, in our view VA’s mission and its unique patient population create a special risk that permitting VA practitioners to offer palliative sedation when the patient’s suffering cannot be defined in reference to clinical criteria could erode public trust in the agency. Therefore, as a committee we do not endorse this practice. We acknowledge that restricting the availability of palliative sedation in this way may fail to address the needs of some patients whose suffering cannot be relieved by other means. We commend the commitment of health care professionals and other staff throughout VHA to provide open, empathic support even as clinical interventions fall short of alleviating the individual’s suffering. We find the conclusion reached by the ACP-ASIM in its position paper on physician-assisted suicide cogent in our context:

[W]hen the patient’s suffering is interpersonal, existential, or spiritual, the tasks of the physician are to remain present, to “suffer with” the patient in compassion, and to enlist the support of clergy, social workers, family, and friends in healing the aspects of suffering that are beyond the legitimate scope of medical care.⁵⁶

The Committee concludes that palliative sedation should not be used to treat existential suffering in the absence of severe, refractory clinical symptoms.

5. May Palliative Sedation Be Provided to Patients Who Lack Decision-Making Capacity?

Because the decision to sedate a patient to unconsciousness and maintain that state until he or she dies is a serious one, some might argue that palliative sedation should be considered only for patients who can consent to it themselves. However, confining palliative sedation to patients who have decision-making capacity risks excluding many patients whose suffering cannot be relieved by other means for whom surrogates are empowered to make all other treatment decisions. Indeed, many patients for whom palliative sedation would be considered will already have lost the capacity to participate in shared decision making due to the progression of their underlying condition and/or the effects of treatment or unmanageable symptoms. To deny a patient’s surrogate the possibility of consenting to palliative sedation undermines the surrogate’s role in shared decision making and in effect undermines the patient’s right to choose this intervention.

The Committee concludes that palliative sedation may be provided to patients who lack decision-making capacity with the informed consent of the authorized surrogate decision maker.

CONDITIONS FOR ETHICALLY SOUND PRACTICE

At various points throughout the foregoing discussion we have noted the important role in palliative sedation of professionals from multiple disciplines. We have also stressed that providing high quality palliative care is a prerequisite to decisions about palliative sedation. These fundamental conditions for ethically appropriate practice of palliative sedation are well recognized in the professional community.^{11,12,15,19,22,23,47,48} Consultation with practitioners expert in pain and symptom management is essential to assure that a patient's symptoms truly are refractory before palliative sedation is considered,^{11,12,15,22,23,48} and to initiate and monitor sedation.¹² Likewise patients must be assured access to expert psychological and spiritual assessment and support.^{11,15,23,47,48,57}

The decision to sedate a dying patient to unconsciousness for the duration of his or her life is a grave one and should be made only after careful clinical evaluation and thoughtful deliberation, and must be implemented with appropriate monitoring and supervision.

RECOMMENDATIONS

Although debate continues about how broadly to define the range of circumstances in which palliative sedation is appropriate, the emerging professional and ethical consensus is clear: Palliative sedation is an ethically appropriate therapy of last resort for patients who are experiencing severe, unremitting, refractory clinical symptoms at the end of life. The National Ethics Committee therefore recommends that VA adopt policy that:

- (1) Permits the administration of palliative sedation (by definition, as a last resort) only:
 - (a) when severe pain or other clinical symptoms (e.g., dyspnea, nausea and vomiting, agitated delirium) is/are not ameliorated by aggressive symptom-specific interventions that are tolerable to the patient;
 - (b) for patients who have entered the final stages of the dying process and who have a DNR order;
 - (c) with the signed informed consent of the patient, or surrogate if the patient lacks decision-making capacity, as required by VA policy for treatments or procedures involving general anesthesia.⁵⁸
- (2) Establishes safeguards to protect patients' interests and assure consistent, high quality care by:
 - (a) providing for consultation with experts in palliative medicine, psychiatry or clinical psychology, and spiritual care as appropriate in the decision-making process;
 - (b) clarifying with the patient and/or surrogate the plan of care regarding:
 - (i) concurrent life-sustaining treatment (including, but not limited to, artificially administered nutrition and hydration),
 - (ii) regular assessment of the patient's clinical status and ongoing eligibility for palliative sedation, and
 - (iii) health care professionals' obligation to discontinue deep sedation in the event the patient's status improves;
 - (c) assuring the participation of a health care professional with appropriate expertise in palliative care and the administration of palliative sedation;
 - (d) assuring that the patient continues to receive appropriate care and hygiene;
 - (e) monitoring sedation to assure adequate and continuous unconsciousness while avoiding inappropriate or unnecessary untoward drug effects;
 - (f) documenting the rationale for palliative sedation and the informed consent conversation appropriately in the patient's health record; and

- (g) establishing clear procedures for resolving disagreements about treatment plans or specific treatment decisions, including ethics consultation when appropriate.

REFERENCES

1. National Consensus Project for Quality Palliative Care. *Clinical Practice Guidelines for Quality Palliative Care*, 2004. Available at <http://www.nationalconsensusproject.org>; accessed December 3, 2004.
2. Chiu TY, Hu WY, Lue BH, Cheng SY, et al. Sedation for refractory symptoms of terminal cancer patients in Taiwan. *Journal of Pain and Symptom Management* 2001;21(6):467–72.
3. Morita T, Tsuneto S, Shima Y. Definition of sedation for symptom relief: a systematic literature review and a proposal of operational criteria. *Journal of Pain and Symptom Management* 2002;24(4):447–53.
4. Morita T, Chinone Y, Ikenaga M, et al. Ethical validity of palliative sedation therapy: A multicenter, prospective, observational study conducted on specialized palliative care units in Japan. *Journal of Pain and Symptom Management* 2005;30(4):308–19.
5. Kaldjian LC, Jekel JF, Bernene JL, et al. Internists' attitudes towards terminal sedation in end of life care. *Journal of Medical Ethics* 2004;30:499–503.
6. National Hospice and Palliative Care Organization. *Total Sedation: A Hospice and Palliative Care Resource Guide*. Alexandria, VA: NHPCO;2000.
7. American Academy of Hospice and Palliative Medicine. *Statement on Sedation at the End-of-Life*. American Academy of Hospice and Palliative Medicine, September 13, 2002. Available at <http://www.aahpm.org/positions/sedation.html>; accessed August 30, 2005.
8. Quill TE, Byock IR, for the ACP-ASIM End-of-Life Care Consensus Panel. Responding to intractable terminal suffering: The role of terminal sedation and voluntary refusal of food and fluids. *Annals of Internal Medicine* 2000;132:408–414.
9. American Medical Association. Brief of the American Medical Association, the American Nurses Association, and the American Psychiatric Association, et al. as *Amici Curiae* in Support of Petitioners. *Vacco v. Quill et al* (US S. Ct. No. 95-1858 November 12,1996).
10. Quill TE, Coombs Lee B, Nunn S. Palliative treatments of last resort: Choosing the least harmful alternative. *Annals of Internal Medicine* 2000;132:488–93.
11. Quill TE, Lo B, Brock DW. Palliative options of last resort: A comparison of voluntarily stopping eating and drinking, terminal sedation, physician-assisted suicide, and voluntary active euthanasia [health law and ethics]. *JAMA* 1997;278(3):2099–2104.
12. Braun TC, Hagen NA, Clark T. Development of a clinical practice guideline for palliative sedation. *Journal of Palliative Medicine* 2003;6(3):345–50.
13. Muller-Busch HC, Andres I, Jehser T. Sedation in palliative care—A critical analysis of 7 years experience. *BMC Palliative Care* 2003;2(2). Available at <http://www.biomedcentral.com/1472-584X/2/2>; accessed August 30, 2005.
14. Taylor RM. Is terminal sedation really euthanasia? *Medical Ethics Newsletter* 2003;10(1):3,8.
15. Cherny NI, Portenoy RK. Sedation in the management of refractory symptoms: Guidelines for evaluation and treatment. *Journal of Palliative Care* 1994;10(2):31–38.
16. Hospice and Palliative Nurses Association. *Palliative Sedation at End of Life*. Hospice and Palliative Nurses Association, June 2003. Available at http://www.hpna.org/pdf/Palliative_Sedation_Position_Statement_PDF.pdf; accessed August 30, 2005.
17. Rousseau P. Palliative sedation [guest editorial]. *American Journal of Hospice and Palliative Care* 2002;19:295–97.
18. Goldstein-Shirley J, Jennings B, Rosen E. Total sedation in hospice and palliative care. Unpublished discussion paper prepared for the Ethics Committee of the National Hospice Association, November 23, 1999.

19. Hallenbeck JL. Terminal sedation for intractable distress: Not slow euthanasia but a prompt response to suffering. *Western Journal of Medicine* 1999;171:222–223.
20. Cowan JD, Palmer TW. Practical guide to palliative sedation. *Current Oncology Reports* 2002;4:242–49.
21. Burt RA. The Supreme Court speaks—not assisted suicide but a constitutional right to palliative care. *New England Journal of Medicine* 1997;337:1234–36.
22. Schuman Z, Lynch M, Abrahm JL. Implementing institutional change: An institutional case study of palliative sedation. *Journal of Palliative Medicine* 2005;8:666–76.
23. Salacz M, Weissman DE. *Fast Fact and Concept #106: Controlled Sedation for Refractory Suffering—Part I*. End-of-Life Physician Education Resource Center, 2004. Available at <http://www.eperc.mcw.edu>; accessed January 27, 2005.
24. Greene WR, Davis WH. Titrated intravenous barbiturates in the control of symptoms in patients with terminal cancer. *Southern Medical Journal* 1991;84:332–7.
25. Fainsinger RL, Waller A, Bercovici M, et al. A multicentre international study of sedation for uncontrolled symptoms in terminally ill patients. *Palliative Medicine* 2000;14:257–265.
26. Kohara H, Ueoka H, Takeyama H, et al. Sedation for terminally ill patients with cancer with uncontrollable physical distress. *Journal of Palliative Medicine* 2005;8:20–25.
27. Lo B, Rubenfeld G. Palliative sedation in dying patients: “We turn to it when everything else hasn’t worked” [Perspectives on care at the close of life]. *JAMA* 2005;294:1810–16.
28. Rousseau P. Palliative sedation and sleeping before death: A need for clinical guidelines? [editorial] *Journal of Palliative Medicine* 2003;6(3):425–27.
29. Cherny NI. Commentary: Sedation in response to refractory existential distress: Walking the fine line. *Journal of Pain and Symptom Management* 1998;16(6):404–06.
30. Billings JA, Block SD. Slow euthanasia. *Journal of Palliative Care* 1996;12(4):21–30.
31. Kingsbury RJ, Ducharme HM. The debate over total/terminal/palliative sedation. The Center for Bioethics and Human Dignity, January 24, 2002. Available at http://www.cbhd.org/resources/endoflife/kingsbury-ducharme_2002-01-24.htm; accessed September 26, 2005.
32. Sulmasy DP, Pellegrino ED. The rule of double effect: Clearing up the double talk. *Archives of Internal Medicine* 1999;159:545–49.
33. Lynn J. Terminal sedation [letter to the editor]. *New England Journal of Medicine* 1998;338:1230.
34. Sykes N, Thorn A. Sedative use in the last week of life and the implications for end-of-life decision making. *Archives of Internal Medicine* 2003;163:341–44.
35. Quill TE, Dresser R, Brock DW. The rule of double effect—A critique of its role in end-of-life decision making [sounding board]. *New England Journal of Medicine* 1997;337:1764–71.
36. Rousseau P. The ethical validity and clinical experience of palliative sedation. *Mayo Clinic Proceedings* 2000;75:1064–69.
37. Jansen LA, Sulmasy DP. Sedation, alimentation, hydration, and equivocation: Careful conversation about care at the end of life. *Annals of Internal Medicine* 2002;136:845–49.
38. 521 U.S. 793 (1997) and 521 U.S. 702 (1997), respectively.
39. Terminal sedation vs. PAS: Difference just semantics? *Medical Ethics Advisor* 2005;8:91–93.
40. Gillick MR. Terminal sedation: An acceptable exit strategy? *Annals of Internal Medicine* 2004;141(3):236–37.
41. Sheldon T. Dutch euthanasia law should apply to patients “suffering through living,” report says. *British Medical Journal* 2005;330:61.
42. Morita T, Ikenaga M, Adachi I, et al. Family experience with palliative sedation therapy for terminally ill cancer patients. *J Pain Symptom Manage*. 2004 Dec;28(6):557–65.

43. Foley KM. Competent care for the dying instead of physician-assisted suicide [editorial]. *New England Journal of Medicine* 1997;336:53–58.
44. Lunney JR, Lynn J, Foley DJ, et al. Patterns of functional decline at the end of life. *JAMA* 2003;289:2387–92.
45. Glare P, Virik K, Jones M, et al. A systematic review of physicians' survival predictions in terminally ill cancer patients. *British Medical Journal* 2003;327:195–200.
46. Lamont EB, Christakis NA. Complexities in prognostication in advanced cancer: "To help them live their lives the way they want to" [Perspectives on care at the close of life]. *JAMA* 2003;290:98–104.
47. Rousseau P. Existential suffering and palliative sedation: A brief commentary with a proposal for clinical guidelines. *American Journal of Hospice and Palliative Care* 2001;18(3):151–53.
48. Salacz ME, Weissman DE. *Fast Fact and Concept #107: Controlled Sedation for Refractory Suffering—Part II*. End-of-Life Physician Education Resource Center, 2004. Available at <http://www.eperc.mcw.edu>; accessed January 27, 2005.
49. Hospice and Palliative Care Federation of Massachusetts. *Palliative Sedation Protocol: A Report of the Standards and Best Practices Committee*. Norwood, MA: Hospice and Palliative Care Federation of Massachusetts;2004. Available at http://www.hospicefed.org/hospice_pages/reports/pal_sed_protocol.pdf; accessed August 30, 2005.
49. Orentlicher D. The Supreme Court and Physician-Assisted Suicide – Rejecting Assisted Suicide but Embracing Euthanasia. *New England Journal of Medicine* 1997;337:1236–39.
50. Hallenbeck JL. Terminal sedation: ethical implications in different situations. *Journal of Palliative Medicine* 2000;3(3):313–20.
51. Cassell EJ. Diagnosing suffering: A perspective. *Annals of Internal Medicine* 1999;131:531–34.
52. Block SD. Assessing and managing depression in the terminally ill patient. *Annals of Internal Medicine* 2000;132:210–18.
53. Morita T, Tsunoda J, Inoue S, Chihara S. Terminal sedation for existential distress. *American Journal of Hospice and Palliative Care* 2000;17(3):189–95.
54. Jonsen AR, Siegler M, Winslade WJ. *Clinical Ethics*. 2nd ed. New York, NY: Macmillan Publishing Co.;1986.
55. Callahan D. When self-determination runs amok. *Hastings Center Report* 1992;22(2):52–5.
56. Snyder L, Sulmasy DP, for the Ethics and Human Rights Committee, ACP–ASIM. Physician-assisted suicide [position paper]. *Annals of Internal Medicine* 2001;135(3):209–16.
57. Block SD. Psychological considerations, growth, and transcendence at the end of life: The art of the possible. *JAMA* 2001;285:2898–2905.
58. U.S. Department of Veterans Affairs. VHA Handbook 1004.1: *Informed Consent for Clinical Treatments and Procedures*. January 2003.
59. Zablocki VA Medical Center. *Palliative Care and Oncology: Palliative Sedation*. ECC Memorandum No. 17, December 2004.