

NHPCO *Special Article*

National Hospice and Palliative Care Organization (NHPCO) Position Statement and Commentary on the Use of Palliative Sedation in Imminently Dying Terminally Ill Patients

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Key Words

Palliative sedation, hospice care, palliative care, terminal care, ethics, medical ethics, intractable pain, position statement, practice guideline, decision making

Introduction

The National Hospice and Palliative Care Organization (NHPCO) endorses the

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definition of “palliative care” put forth by the National Quality Forum.¹ It reads:

Palliative care refers to patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choice.¹ (p. 3)

The purpose of palliative care is to provide aggressive symptom management, supported decision making, and, when appropriate, optimal end-of-life care. Palliative care is *family-centered* although in those cases in which the needs and preferences of the family counter the best interests of the patient, the needs of the patient are primary. In rare cases where patient suffering is especially resistant to other forms of treatment, one of the therapies available to palliative care teams is palliative sedation.

Palliative sedation is the lowering of patient consciousness using medications for the

express purpose of limiting patient awareness of suffering that is *intractable* and *intolerable*. For the limited number of *imminently dying* patients who have pain and suffering that is (a) unresponsive to other palliative interventions less suppressive of consciousness and (b) intolerable to the patient, NHPCO believes that palliative sedation is an important option to be considered by health care providers, patients, and families. As this practice continues to be addressed in the professional and lay literatures, discussion of palliative sedation is often framed in ethical terms. The following statement and commentary seek to clarify the position of NHPCO on the use of palliative sedation for patients at the end of life, recommend questions and issues to be addressed in each case for which palliative sedation is being considered, and assist health care organizations in the development of policies for the use of palliative sedation. This statement addresses the use of palliative sedation only for patients who are *terminally ill* and whose death is imminent.

Position Statement

1. Availability

Palliative sedation is an important tool among the spectrum of therapies available in hospice and palliative care. For the small number of imminently dying patients whose suffering is intolerable and *refractory*, NHPCO supports making the option of palliative sedation, delivered by highly trained health care professionals, available to patients.

2. Proportionality

The goal of palliative sedation is to provide relief from symptoms that are otherwise intolerable and intractable. Since the goal is symptom relief (and not unconsciousness *per se*), sedation should be titrated to the minimum level of consciousness reduction necessary to render symptoms tolerable. For some patients, this may be total unconsciousness. For most, however, it will be less than total unconsciousness, allowing

the patient to rest comfortably but to be aroused.

3. Interdisciplinary Evaluation

Palliative sedation is a medical treatment. As such, there must be a physician with expertise in palliative care leading the intervention. Suffering at the end of life, however, is a phenomenon that may respond best to the efforts of a highly skilled interdisciplinary team. As such, NHPCO recommends the practice of convening an interdisciplinary conference specifically about the use of palliative sedation for each patient with whom it is being considered. Such conferences should include practitioners from many disciplines who can speak to the modalities available in their disciplines and discuss the degree to which they have been tried and exhausted. Expertise is required in pharmacology, management of pain and other symptoms, interventions targeted at the aspects of suffering that are psychological, interpersonal, spiritual, and other domains as relevant to each individual patient. In all cases, care must be patient- and family-centered.

4. Education

In addition to expertise in palliative care, those involved in palliative sedation must have training and competence in this particular intervention. As with all health care providers, those involved in the process of providing palliative sedation should be engaged in ongoing education. This education should address symptom assessment and management as well as the ethical considerations related to use of palliative sedation. Education must also address family-centered care.

5. Concerning Existential Suffering

Increasing discussion in the hospice and palliative care literature about the use of palliative sedation for existential suffering reflects the recognition that suffering can occur in all aspects of the person—even when physical symptoms are well controlled. As with any other type of suffering, NHPCO believes that

hospice and palliative care professionals have an ethical obligation to respond to existential suffering using the knowledge, tools, and expertise of the interdisciplinary team. Whether palliative sedation should be a part of that response is an important, growing, and unresolved question. Having carefully reviewed the data and arguments for and against using palliative sedation for existential suffering, the Ethics Committee is unable to reach agreement on a recommendation regarding this practice. NHPCO strongly urges providers to carefully consider this question and supports further ethical discussion. NHPCO also encourages research within and across disciplines to build an evidence base supporting multiple interventions for existential suffering.

6. Relationship to Euthanasia and Assisted Suicide

Properly administered, palliative sedation of patients who are imminently dying is not the proximate cause of patient death, nor is death a means to achieve symptom relief in palliative sedation. As such, palliative sedation is categorically distinct from euthanasia and assisted suicide.

Commentary

Knowledge about symptom management has burgeoned over recent decades. Most symptoms can be managed with an excellent knowledge of physiology, pharmacology, and complementary therapies. NHPCO recommends that patients with complex care needs receive care from palliative care experts in conjunction with care provided by their primary care providers and other specialists as needed. This might require consultation of experts outside of the hospice team. However, expert consultation is always recommended when considering interventions or evaluating symptoms with which a hospice team has little experience.² In this commentary, definitions of terms pertinent to the use of palliative sedation in the palliative care of imminently dying patients are offered. In addition, indications for the use of palliative sedation, an overview

of ethical issues related to its use, and processes that can be implemented to address those issues will be discussed.

Definitions

Euthanasia refers to “the administration of a lethal agent by another person to a patient for the purpose of relieving the patient’s intolerable and incurable suffering.”³ (p. 2229) That is, euthanasia is intentionally ending the life of another person, usually with the goal of alleviating or avoiding suffering.

Existential suffering is suffering that arises from a loss or interruption of meaning, purpose, or hope in life.^{4,5} Importantly, there is no widely agreed on definition of existential suffering. In the palliative sedation literature, it is often used to connote suffering that is not physical in etiology. In this document, the term is used to refer to suffering arising from a sense of meaninglessness, hopelessness, fear, and regret in patients who knowingly approach the end of life.

Family-centered care is care that treats the patient and the patient’s intimates as recipients of care. It is based on the notion that suffering and dying are phenomena that find meaning in, and are experienced by, patients and the powerful web of relationships in which they are situated. Palliative care is family-centered insofar as it acknowledges that, frequently, a patient’s suffering and death cannot be sufficiently palliated by treating the patient in isolation from her or his circle of intimates.^{6–8}

Imminent death. Although pervasive in the hospice and palliative care literature, “imminence” of death is rarely defined. Consistent with the few articles in the literature that define imminence,⁹ this document uses the term to mean a prognosis of death within 14 days. This definition is compatible with the commonly used terminology of death within “days to weeks.”

Intolerable suffering is suffering that patients perceive to be unbearable; only the patient can identify when suffering has become intolerable. It is the responsibility of the health care team to use reliable and valid assessment measures to determine the level of suffering that the patient is likely to be experiencing.^{10–12} When patients are unable to communicate, these assessments should be

evaluated with families to consider whether, based on the known values and wishes of the patient, suffering has reached a level that the patient would declare intolerable were the patient able to communicate.¹³

Intractable suffering is suffering that has not adequately responded to all trialed interventions and for which additional interventions are either unavailable or impractical (e.g., the patient is expected to die before an intervention could become effective). (See also “Refractory suffering”.)

Palliative sedation (also called **palliative sedation therapy**) is the controlled administration of sedative medications to reduce patient consciousness to the minimum extent necessary to render intolerable and refractory suffering tolerable.^{14,15}

Physician-assisted suicide (also called **assisted suicide**) is “when a physician facilitates a patient’s death by providing the necessary means and/or information to enable the patient to perform the life-ending act (e.g., the physician provides sleeping pills and information about the lethal dose, while aware that the patient may commit suicide).”³ (p. 2229) In cases of assisted suicide, medications are self-administered by the patient, thereby distinguishing it from euthanasia.

Proportionality. The principle of proportionality is used to argue that the benefits of any intervention should outweigh the burdens of that intervention. In particular, proportionality requires that interventions with any risk of harm should be administered only to the degree necessary to confer the desired amount of therapeutic benefit. Proportionality guides the dose-response relationship in the prescription of medication; patients need enough medication to achieve the desired effect but not so much that significant adverse side effects will result. In palliative sedation, proportionality is used to argue that any level of sedation in excess of that required to render suffering tolerable as defined by the patient cannot be justified.¹⁶

Refractory suffering is suffering that “cannot be adequately controlled despite aggressive efforts to identify tolerable therapy that does not compromise consciousness.”¹⁷ (p. 31) This could be because the suffering has been insufficiently responsive to interventions less suppressive of consciousness or because “on the basis of the patient’s wishes and physical conditions, there

are no other methods that will be effective within the allowed time frame and the possibility of complications and degree of invasion are tolerable for the patient.”¹³ (p. 720) (See also “Intractable suffering”.)

Respite sedation is a term used by some as interchangeable with palliative sedation. Procedurally, however, respite sedation is administered differently than palliative sedation. Respite sedation is induced for a predetermined period of time to give the patient respite from intractable refractory suffering. At the end of that period of time, sedation is reduced to allow the patient to awaken and assess whether the symptom burden has lifted, and determine if sedation is still required to effectively address suffering.

Suffering signifies the broad range of ways in which patients can experience threats to their “personhood.”^{18,19} Although often caused by—or experienced simultaneously with—physical pain, suffering can be the result of injuries to many aspects of the self, including, but not limited to, the physical, psychosocial, spiritual, temporal, and existential realms.

Terminally ill is used in the hospice and palliative care community to refer to a life expectancy of six months or less.

Terminal sedation is an older term for palliative sedation. Its use has fallen out of favor because of the way in which the word “terminal” was misinterpreted to imply that the sedation itself caused or hastened death.

Indications and Recommended Processes

Indications for palliative sedation most commonly include pain, dyspnea, delirium, and restlessness that have been refractory to treatment and declared by the patient—or the patient’s surrogate—to have risen to the level of intolerable suffering.^{14,20–24} There are reliable and valid tools to assess, and algorithms to manage, most symptoms in imminently dying patients. It is the responsibility of those clinicians considering the use of palliative sedation to integrate appropriate tools into the care of patients with these symptoms before the use of palliative sedation. “Existential suffering,” addressed below, is also offered by some as an appropriate indication for palliative sedation.

Although it is beyond the purview of this organization to make pharmacologic recommendations, NHPCO recognizes that experts in

anesthesiology and in pain medicine have made specific recommendations. NHPCO also recognizes that many of the medications used in palliative sedation can create their own burden and, if administered incorrectly, can even cause death.²¹ As such, judicious use should be guided by an evidence-based clinical protocol and ongoing monitoring by clinicians who are experienced with these medications and palliative sedation. Considerations of effectiveness and safety “to prevent the mislabeling of palliative sedation as ‘euthanasia by proxy’” are essential.²⁵ (p. e2)

Continuation of Concurrent Life-Sustaining Therapies

Implementation of palliative sedation cannot be done without simultaneous consideration of other therapies being received by, or available to, the patient. In this document, palliative sedation is being considered for the patient whose death is imminent (defined as expected in less than two weeks). NHPCO recommends that all patients receiving palliative sedation have a do-not-resuscitate/do-not-attempt-resuscitation order in effect.^{26,27}

For patients undergoing sedation whose death is imminent, it should be extremely rare for therapies such as dialysis, chemotherapy, or transfusions to be continued once palliative sedation has been initiated. Medications that are likely to contribute to ongoing patient comfort should be continued (see also “Proximity to Death” below).

Concerning Artificial Nutrition and Hydration

Patients being lightly sedated may be able to eat or drink as desired. Patient-controlled intake of food and fluids is unlikely, however, with moderate to deep sedation. Consideration of whether to begin or continue artificial nutrition and hydration (ANH) should be discussed with the patient and family before beginning palliative sedation. Any decision about ANH should be made separately from a decision about palliative sedation.^{14,20} Patients undergoing palliative sedation may or may not have already in place some means of vascular access for the administration of medication. Thus, the question of burden of access for parenteral administration of nutrition or hydration should be considered. If patients

or families are considering continuing enteral administration, the balance of benefits and burdens should be thoroughly reviewed. An ethically relevant consideration is whether the administration of fluids will relieve or exacerbate symptoms.²⁸ Although provision of fluids has been shown to alleviate some symptoms in some patients, fluid overload causes its own set of symptoms. Authors of a Cochrane review concluded, “There are insufficient good quality studies to make any recommendation for practice with regard to the use of medically assisted hydration in palliative care patients.”²⁹ Of note, these recommendations were made about the general use of ANH and did not apply specifically to patients undergoing palliative sedation.

Proximity to Death

There is debate in the literature concerning the relevance of a patient’s proximity to death as a prerequisite for palliative sedation. An informal review of institutional protocols by NHPCO Ethics Committee members reveals that many policies require that patients be imminently dying—that is, within “hours to days” of death—before palliative sedation is considered. Authors of one published review note that proximity to death is sometimes central to defining the intervention itself: “Palliative sedation is the intentional lowering of consciousness of a patient in the last phase of his or her life.”²⁴ (p. 667) Some use the phrase “actively dying” to demarcate the time when palliative sedation is appropriate. This term is used in widely different ways to encompass time periods from minutes to months, although more commonly “actively dying” refers to a time of hours to days. Others argue that proximity to death is not as significant as the intensity of a patient’s symptom distress.^{30,31}

NHPCO argues that, as physicians are often inaccurate in their prognostication,^{32,33} identifying an appropriate time frame for the use of palliative sedation may lead to suboptimal use of palliative sedation. Indeed, although some may argue that proximity to death is an important consideration, NHPCO believes that such consideration is always secondary to the primary goal of all hospice and palliative care: safe and effective palliation of symptom distress in accordance with clinical indications and the goals of the patient. Therefore, there

may be some situations in which patient suffering is so severe and refractory to other interventions that proximity to death becomes far less important than the relief of suffering itself.

However, if sedation is continuous, precludes oral intake, and artificial nutrition and hydration are not going to be administered, it is possible that dehydration could become a contributing cause of death for patients with a life expectancy of greater than two weeks. In such cases, another set of ethical and philosophical questions is raised. It is for this reason that NHPCO limits the scope of this position statement to patients whose death is imminent.

Level of Sedation

The administration of sedation should be guided by the level of consciousness reduction required to sufficiently relieve symptoms. Sedation exists on a spectrum. Palliative sedation is undertaken with the goal of alleviation of symptom burden. For most patients, this occurs when patients are sleepy but rousable. For others, symptom relief does not occur until the patient is deeply sedated (unrousable; unconscious). NHPCO recommends that sedation be carefully controlled and titrated proportionately, such that the extent of sedation is the minimum required to render symptom distress tolerable to the patient. Verkerk et al.²⁴ (p. 667) emphasize the need for proportionality, proper indications, and adequacy “so that a peaceful and acceptable situation is created.” As with most medical therapies, a “one size fits all” approach is inadequate. A 2005 study indicated that palliative sedation was inadequate in providing symptom relief in 17% of patients.³⁴ Davis³⁵ recommends use of a sedation scale to ensure that, when palliative sedation is used, sedation is adequate to achieve symptom relief.

Education and Clinician Support

In addition to expertise in palliative care, those involved in the consideration and implementation of palliative sedation must have additional and specific competence in providing palliative sedation. All those potentially participating in the assessment for and/or provision of palliative sedation should be involved in ongoing education, as the evidence base and

practice recommendations for palliative sedation are rapidly evolving. This education should address symptom assessment and management, review evidence-based protocols for inducing sedation, and discuss the ethical considerations of the process and the procedure of palliative sedation. Education must also address family-centered care.

NHPCO recommends that, beyond technical competence, health care professionals working in hospice and palliative care settings understand the potential for misunderstanding and the highly charged emotions that can accompany the practice of palliative sedation. Providers on the interdisciplinary team must be familiar with the wide array of modalities available to address patient suffering and be able to help patients, families, and team members ensure that less invasive options have been exhausted before initiating palliative sedation. Education of team members must include opportunities to address staff concerns about palliative sedation—especially by explaining the important distinctions between palliative sedation, assisted suicide, and euthanasia—before clinicians are asked to provide this therapy.

Caring for imminently dying patients who are suffering intensely can exert a significant emotional toll on families and even the most experienced clinicians. In particular, such suffering can create an environment in which the risk for countertransference and feelings of caregiver helplessness is especially high. Careful attention must be paid to acknowledging and addressing these phenomena so that decisions regarding sedation can be made on the basis of the *patient's* suffering and wishes and not the countertransference or feelings of helplessness of family members or clinicians. NHPCO recommends that training related to palliative sedation includes content on identifying and managing family and clinician emotions related to intense suffering.

Palliative Sedation Distinguished from Euthanasia and Physician-Assisted Suicide

Although palliative sedation, euthanasia, and physician-assisted suicide ostensibly share the goal of alleviating patient suffering, they are clinically and ethically distinct. Optimal utilization of palliative sedation requires an accurate understanding of these differences. For

patients who are imminently dying, palliative sedation is ethically distinct from euthanasia and physician-assisted suicide in at least three ways:

1. Effect

Properly administered palliative sedation does not involve the “administration of a lethal agent” and does not cause death.^{22,36}

2. Instrument of Relief

Although the goals of palliative sedation, euthanasia, and physician-assisted suicide may be similar—the relief (or prevention) of intractable suffering—the instrument through which those goals are pursued in palliative sedation is categorically distinct from those used in euthanasia or physician-assisted suicide. In palliative sedation, relief of suffering is sought via the minimum level of consciousness reduction required to decrease awareness of distress to a level tolerable as defined by the patient. In euthanasia and physician-assisted suicide, relief (or prevention) of suffering is sought via the death of the patient. In palliative sedation, death is not used as a means to achieve symptom relief. Rather, death occurs at some point *after* the relief of suffering is achieved.

3. Legality

In the United States, euthanasia is not legal. As this statement goes to press, physician-assisted suicide is currently a legal option for patients in Oregon, Washington, and Montana (under review). Palliative sedation is legal and is an appropriate clinical option throughout the United States. Indeed, the U.S. Supreme Court has acknowledged palliative sedation as a safe, legal, and reasonable alternative to assisted suicide.³⁷ Palliative sedation does not ask patients, family members, or health care providers to violate the law. Although an intervention’s legal status and ethical status are not necessarily equivalent, *asking* health care providers as a part of good practice to *violate* the law in jurisdictions where

euthanasia or assisted suicide is illegal risks significant negative consequences for all involved. Such consequences are ethically relevant.

Reluctance to use palliative sedation often exists because of a belief that it hastens death. Optimally done in imminently dying patients, however, palliative sedation does not hasten death.^{14,20} Rietjens et al.²² found no difference in the survival times between patients who were sedated and those who were not. As evidenced by their studies of opioids and sedatives at the end of life, Sykes and Thorns²³ concluded that appropriate knowledge and skill allows the administration of appropriate doses of medication to manage symptoms without hastening death. Similar findings were reported by Kohara et al.³⁸

Frequency of Use

Palliative sedation should be used rarely.²⁵ Prevalence of the use of palliative sedation in terminally ill patients has been reported between 1% and 52%.^{14,20,22,23} NHPCO supports the use of palliative sedation only in cases where alternative interventions have been exhausted or are otherwise inadvisable (e.g., when the patient is expected to die before an alternative intervention is expected to become effective). As such, NHPCO regards the upper end of this range as problematic. Although the prevalence of palliative sedation will appropriately vary in correlation with the complexity of illness and severity of suffering in the patient population of each care service, a high percentage of patients receiving palliative sedation should be cause for concern. Such a phenomenon could be an indicator that the full spectrum of interdisciplinary interventions for suffering is not being effectively explored and trialed.

Palliative Sedation and Existential Suffering

NHPCO acknowledges deep disagreement among highly skilled and ethically informed palliative care specialists regarding the appropriateness of palliative sedation in imminently dying patients whose intolerable refractory suffering is primarily nonphysical in origin. Difficulties in discussing interventions for existential suffering are compounded by the lack of a clear, widely used definition of “existential suffering” itself. Such suffering also

poses the following particular challenges related to palliative sedation.

1. Existential suffering may occur much earlier in the disease trajectory (i.e., before death is imminent) than other kinds of suffering. As such, if patients with a life expectancy exceeding two weeks require sedation which precludes oral intake and refuse ANH, many experts believe that such sedation can become a contributing cause of death.
2. The availability of, and evidence supporting, interventions of any kind—medical or otherwise—for existential suffering in imminently dying patients is extremely limited and uneven. As such, palliative care specialists who argue that psychosocial interventions are more appropriate for such suffering than palliative sedation are unable to identify or recommend specific concrete interventions that are widely available and based on evidence of demonstrated effectiveness.
3. Unlike intractable and refractory suffering which is primarily physical and usually proceeds on a trajectory of increasing intensity, existential suffering can be highly dynamic, following no predictable pattern of severity. Therefore, suffering that is intractable and refractory today may be far less so tomorrow or the next day.

NHPCO believes that the primary ethical duty of hospice and palliative care professionals is to acknowledge, address, and (when possible) relieve the suffering of terminally ill patients in a manner that is consistent with the norms and values of patients, families, and health care professionals. The lack of a widely accepted definition of “existential suffering,” combined with the difficulties articulated in points 1 to 3 above, has resulted in the NHPCO Ethics Committee being unable to reach consensus on a recommendation regarding the use of palliative sedation for suffering that is primarily nonphysical in origin. The organization urges great caution and multiple careful discussions among interdisciplinary team members, families, and patients when considering the use of sedation for such

suffering. The dynamic nature of existential suffering suggests that trials of respite sedation, rather than continuous sedation, may be an appropriate place to begin if a decision to proceed with sedation is reached.²⁸ In these cases, in addition to a medically led interdisciplinary team with clinical expertise in palliative care, and an individual review of each case, NHPCO recommends consulting mental health and spiritual care experts with experience in the realm of existential suffering.

Case Review and Utilization Review

Given the importance of monitoring frequency noted above, NHPCO recommends regular review of the utilization of palliative sedation. Most institutions have a mechanism for regular review of policies and specific practices. This often occurs under a continuous quality improvement model. We recommend formalization of the process of review. Care organizations should determine an appropriate schedule of review (i.e., quarterly, semiannually, and annually) based on 1) frequency of utilization, 2) varying level of acuity/complexity in the patient population, and 3) level of team experience with severe symptom management and palliative sedation. Review should examine each case and explore trends in:

1. indications/symptoms for which palliative sedation was offered;
2. therapies (medication, doses, and other treatments) that had been trialed to manage symptoms before sedation;
3. the patient’s and family’s understanding of the goals of the therapy, and the nature of the informed consent discussion with the patient and family;
4. decisions regarding the continuation of other life-sustaining interventions, including nutrition and hydration;
5. the titration of sedation, including
 - depth of sedation required for symptom relief and how this was measured, and
 - the process by which symptom distress was evaluated during titration;
6. ways in which the family was supported during and after sedation;

7. ways in which the staff was supported during and after sedation;
8. any complications encountered, and how they were addressed;
9. how the plan for sedation was developed, and how well the plan was followed; and
10. outcomes, including the effectiveness of palliative sedation for the relief of suffering, timing from implementation of palliative sedation to death, whether palliative sedation was reversed before death, and family satisfaction with the process.

Findings should be reviewed in light of each institution's policy regarding palliative sedation and gaps addressed through education, hiring, policy modification, and other remedies as appropriate. Consideration of a quality improvement format may ensure the routine collection and evaluation of appropriate data.

Conclusion

NHPCO recognizes that these guidelines will be difficult to implement in some settings, and that some teams will be resistant to a change in practice or the involvement of others in what has been a routine practice. Whether in an intensive care unit or in a rural hospice, it is incumbent on hospital and hospice administrations and care providers to establish the highest standard of care. Integration of clinical experts is necessary in the same way that it would be in any other complex case.

NHPCO recommends developing and implementing a written institutional policy addressing 1) the criteria and procedure for administering palliative sedation, 2) the concomitant use of life-sustaining therapies, 3) ongoing education regarding evolving clinical evidence and best practices as well as important ethical distinctions between sedation and assisted suicide or euthanasia, and 4) careful monitoring and collection of data related to institutional practices of palliative sedation.

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