OBJECTIVES

1. Define the Purpose of Palliative Sedation (PS)
3. Name 3 challenges staff may voice when introducing Palliative Sedation at your agency
4. Explain the Importance of the Debrief Meeting following a Palliative Sedation case
The Elizabeth Hospice, a Community Based Not for Profit • Founded 1978 • Census 485

2009-2010 Palliative Sedation IDT Task Force Created • Research & Develop POC • Board Approved Staff Education • 3 Palliative Sedation Cases

Topics of Discussion / Challenges • Assisted suicide, hastening death, existential suffering, staff discomfort, euthanasia, one team, ethical questions

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

Introduction
The National Hospice and Palliative Care Organization (NHPCO) endorses the definition of "palliative care" put forth by the National Quality Forum: "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, psychological, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choice. The purpose of palliative care is to provide support and symptom management, supported decision making, and when appropriate, optimal end-of-life care. Palliative care is part of good medical care at any age and at any stage of illness."

Timothy W. Kirk, PhD, and Margaret M. Malin, PhD, RN, FAAN, for the Palliative Sedation Task Force of the National Hospice and Palliative Care Organization Ethics Committee, Department of History & Philosophy, (T.U.), City University of New York – York College, Jamaica, New York, and School of Nursing (M.M.H.), College of Health & Human Services, George Mason University, Fairfax, Virginia, USA
Palliative Sedation Is...

- The monitored use of medications (sedatives, barbiturates, neuroleptics, hypnotics, benzodiazepines or anesthetic medications)

- To relieve refractory and unendurable physical, spiritual and/or psychosocial distress.
  - Refractory: Symptoms that cannot be adequately controlled despite aggressive efforts by the IDT to provide timely, tolerable therapies that do not compromise consciousness.

- For patients with a terminal diagnosis, inducing varied degrees of unconsciousness.

Purpose and Intent

- **Purpose**: Provide comfort and relieve suffering and not to hasten death.

- **Intent**: Relief of suffering and not to end the patient's life.
**Autonomy**

- An individual has the right to decide their course of treatment for themselves according to their values, beliefs or life plan.

- Informed consent is required in order to make autonomous decisions based upon the risks and benefits of any intervention.
**Beneficence**

- Ethical duty to do well as it relates to promoting well being
- The action in itself is morally right
- Intent of the healthcare provider is to do good

**Nonmaleficence**

- Not doing anything intentionally bad, not causing harm
- Only good effects are directly intended
- Distinction between the means and the effects must be envisioned (death must not be the means to the good effect) e.g. drugs relieve severe symptoms even though indirectly producing undesired bad effects such as deprivation of mental properties
When a patient no longer has the capacity to make decisions for him/herself, the principle of fidelity, which includes the promise not to abandon another, allows a designated health care proxy or patient representative who knows the patient's wishes, to make informed decisions regarding the patient's care.

Congruent to the intent of palliative sedation; the outcome is the patient is made unaware of unendurable suffering through sedation.

Sedation is titrated to the minimum level of consciousness reduction necessary to render symptoms tolerable.

For some patients, this may be total unconsciousness; for most it will be less than total unconsciousness, allowing the patient to rest comfortably but to be aroused.
### MEDICAL INDICATIONS

**Beneficence and Nonmaleficence:**
1. Disease and prognosis
2. Goals of treatment
3. Probabilities of success in achieving goals
4. How can patient be benefitted and harm avoided

### PATIENT PREFERENCES

**Respect for Patient Autonomy:**
1. What has the patient expressed?
2. Is the patient capable of understanding consequences of treatments?
3. Prior preferences such as an advanced directive.

### QUALITY OF LIFE

**Beneficence, Nonmaleficence, and Respect for Patient Autonomy:**
1. Prospects for return to "normal" life.
2. Possible personal prejudices about QOL.

### CONTEXTUAL FEATURES

**Loyalty and Fairness:**
1. Are there any conflicts of interest.
2. Are there any religious considerations?
3. Are there other interested parties?
4. Are there institutional pressures?
5. Are there questions of allocation of resources?

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### SUZIE’S SITUATION

47 year old single woman admitted to hospice upon discharge from the hospital for pain and symptom management. She had advanced ovarian cancer and was s/p pelvic exenteration, colostomy, ileostomy, ureterostomy, and with an intrathecal opioid pump in place. She had been hospitalized for bleeding from a fungating lesion of the vagina, receiving transfusions, surgical and palliative consultations.

On admission her PPS was 40%, dependent for 5/6 ADLs, oriented to time, place and person, and having constant pain of about 4/10 despite oral and intrathecal opioids.

Shortly after admission her intrathecal pump became infected and had to be removed, leaving her with only IV and PO routes of medication. She was highly tolerant of opioids and required steadily increasing doses. Despite that she was in such pain that she refused to be moved, even for hygiene. She developed massive stage 4 wounds that became infected and necrotic.
A decision to initiate palliative sedation must be preceded by a comprehensive interdisciplinary team assessment of the patient and a discussion of treatment expectations and options.
### Timeline – Month 1

<table>
<thead>
<tr>
<th>Date</th>
<th>Event Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>10/08/11</td>
<td>Admitted to hospice. Full Code. Pain 4-5 Goal 2. PPS 40%</td>
</tr>
<tr>
<td>10/10/11</td>
<td>Initial MSW visit – discussed self-determined life goals. Hospice Chaplain declined by pt.</td>
</tr>
<tr>
<td>10/14/11</td>
<td>PO Dilaudid increased from 8mg to 16mg every 1-2 hours for pain.</td>
</tr>
<tr>
<td>10/26/11</td>
<td>She has episodes of either severe sweating or clear anal discharge.</td>
</tr>
<tr>
<td>10/28/11</td>
<td>Giant seroma around implanted pump. Explosive drainage when pressed by MD.</td>
</tr>
<tr>
<td>11/02/11</td>
<td>Staph aureus in wound. Doxycycline started. Dressing changes 3-4 /QD. Pain increasing</td>
</tr>
</tbody>
</table>

### Timeline – Month 2

<table>
<thead>
<tr>
<th>Date</th>
<th>Event Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>11/11/11</td>
<td>Significant emesis 3x bile-colored. Unable to tolerate PO meds. Haldol not effective for nausea. IV Dilaudid started, IV Compazine Q 4 hours. Discussion re: need for hospitalization to remove infected pump.</td>
</tr>
<tr>
<td>11/15/11</td>
<td>Surgeon recommends taking pump out ASAP</td>
</tr>
<tr>
<td>11/16/11</td>
<td>POLST completed to remain full code during hospitalization</td>
</tr>
<tr>
<td>11/17-18/11</td>
<td>Admitted to hospital- Intrathecal pump removed, wound vac placed</td>
</tr>
<tr>
<td>11/21/11</td>
<td>NP discussion with patient’s mother and sister regarding patient’s status and s/s of actively dying.</td>
</tr>
<tr>
<td>11/29/11</td>
<td>Now open to chaplain visits “Not her time yet”</td>
</tr>
</tbody>
</table>
TIMELINE – MONTH 3

12/07/11 Chaplain confession session
12/15/11 Patient transitioning from healing to reality of decline, hoping to make it to Christmas
12/22/11 Mother inquired about patient’s fear of dying
12/27/11 Flat on back for two weeks, heavy foul odor from infected wound, unbearable pain (9-10), talked with Mom about dying
12/28/11 DNR signed, tired of fighting, worried about parents coping after her death.

ORAL MORPHINE EQUIVALENT/ DAY – MILLIGRAMS ALL OPIOIDS – PRIOR TO PALLIATIVE SEDATION
**Medical Indications**

- Beneficence and Non-maleficence:
  1. Ovarian cancer s/p pelvic exenteration
  2. Necrosis of entire backside
  3. Constant pain – unable to be moved
  4. Tolerant of opioids
  5. Failed intrathecal pump

**Patient Preferences**

- Respect for Patient Autonomy:
  1. Achieve pain relief
  2. Achieve a “natural death”
  3. “Wake up in the arms of Jesus”
  4. Ready to go NOW!

**Quality of Life**

- Beneficence, Non-maleficence, and Respect for Patient Autonomy:
  1. Immobile
  2. No chance of cure, absent miracle
  3. Odor
  4. Family burden of care

**Contextual Features**

- Loyalty and Fairness:
  1. Spiritual preparation
  2. Family support
  3. Availability of Palliative Sedation protocol
  4. Hospice team prepared

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**First Course of Action**

- The patient maintains a DNR, full No-code status and a physician’s order

- The patient, or if lacking capacity, the patient’s representative, family, physician, hospice medical director, and interdisciplinary team collaborate regarding the appropriate utilization of palliative sedation.
Informed consent is obtained from the patient, or, if lacking capacity, the pt.'s designated representative.

A discussion of the risks and benefits of palliative sedation will be part of the informed consent process.

The written consent for palliative sedation will be ordered by the physician.

Informed Consent/Palliative Sedation

Program Goals: Provide relief for suffering unrelieved by other measures.

Documentation of suffering unrelieved by other measures:

Palliative measures previously attempted and outcome:

PATIENT _____ HEALTH CARE PROXY/PATIENT REPRESENTATIVE _____ (check one)

( ) Able to respond intelligibly to queries
( ) Able to participate rationally in decision-making
( ) Able to articulate the decision

Information Presented:

( ) Nature and progress of stage of terminal illness (prognosis)
( ) Verified DNR status and expected outcome from proposed Palliative Sedation
( ) Effects limitation, side effects, and risks of the proposed Palliative Sedation

( ) I am aware that Dr. ____________________ agrees with the plan to initiate Palliative Sedation.

With knowledge of the risks discussed by the physician(s), I consent to Palliative Sedation for refractory suffering.

[Signatures]
MANAGING AT THE ONSET

- For sedation that is instituted in a patient's home, continuous care registered nursing must be provided for at least 24 hours.

- In all cases of palliative sedation at any location, the hospice physician will be present during the initiation of sedation
  
  **AND**

  A registered nurse will assess the patient continuously during the initiation of therapy

ESSENTIAL SPECIFICS

- Continuous Care staffing availability
- Establish IV access
- Foley consideration
- Daily MD/NP visits
- MSW/Chaplain visits to support caregivers
- Adequate supply of medications—weekend and weekdays
- Verbal reports between triage nurses and nurse at bedside
- Documentation—RN shift summary in clinical notes
- Notify Bereavement of initiation of PS
- Debrief Meeting
Palliative Sedation Checklist

☐ RN Visit / Notify hospice physician / Conventional treatment attempted
☐ Aggressive measures fail to provide relief
☐ Care Team including MD, Chaplain, MSW, RNCM meet to discuss optional PS
☐ Interdisciplinary Team and Hospice MD joint visit to discuss palliative sedation, discuss plan of care, risk and benefits
☐ Physician to fully assess previous drug history
☐ Notify primary physician (if any) that palliative sedation is considered
☐ Hospice MD to collaborate with a second Hospice physician regarding use of palliative sedation
☐ CORE IDG (including entire Care Team)
☐ Managers verify staffing availability
☐ Patient or DPOA agree to palliative sedation/consent form signed
☐ Signed DNR verified / Verify copy of power of attorney (if available)
☐ Establish IV access, PICC line preferred
☐ Insert Foley catheter
☐ Palliative sedation to be implemented at home or facility/Crisis care with RN staffing for 24 hours minimum (If in a facility, discuss financial responsibility with patient/family)
☐ Daily Physician Visits
☐ Review efficacy and goals of treatment as part of physician visit
☐ MSW and Chaplain visits as needed to support caregivers

PALLIATIVE SEDATION MEDICATIONS

Anxiolytic +/- Antipsychotic +/- Analgesic

Midazolam
1 - 5 mg load IV/SC then 0.5 - 1.5 mg/hr IV/SC or
Lorazepam
0.5 - 1 mg/hr IV/SC

Haloperidol
1 mg bolus IV/SC then 0.5 - 1 mg/hr IV/SC

Morphine
1 - 5 mg/hr IV/SC titrate to effect*

Hydromorphone
0.2 - 1 mg/hr IV/SC titrate to effect*

Zaprisadone (Geodon)
5 - 10 mg IM q 2-4 h

*No maximum dose unless patient experiences opioid toxicity not controlled by adjuvants
**TIMELINE – MONTH 4**

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<thead>
<tr>
<th>Date</th>
<th>Event</th>
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<tbody>
<tr>
<td>01/04/12</td>
<td>NP talked with patient and Mom about palliative sedation related to pain, offered to abstain from food and fluids, but this was not acceptable alternative to patient</td>
</tr>
<tr>
<td>01/06/12</td>
<td>Core IDG meeting, interdisciplinary agreement to support patient decision for PS</td>
</tr>
<tr>
<td>01/09/12</td>
<td>3rd day of PS, has awakened twice. Dilaudid now at 50 mg/hr with Ativan 35 mg/hr, after Versed ran out at all pharmacies</td>
</tr>
<tr>
<td>01/11/12</td>
<td>Helicopter flyover and the family went outside to see them and returned to find patient had died. Chaplain condolence calls.</td>
</tr>
<tr>
<td>01/27/12</td>
<td>Debriefing</td>
</tr>
</tbody>
</table>

**Oral Morphine Equivalent/ Day – Milligrams**

<table>
<thead>
<tr>
<th>Date</th>
<th>Oral Morphine Equivalent/ Day – Milligrams</th>
</tr>
</thead>
<tbody>
<tr>
<td>10/8/11</td>
<td>2200</td>
</tr>
<tr>
<td>10/9/11</td>
<td>3000</td>
</tr>
<tr>
<td>10/10/11</td>
<td>6960</td>
</tr>
<tr>
<td>10/11/11</td>
<td>8700</td>
</tr>
<tr>
<td>10/12/11</td>
<td>11920</td>
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<tr>
<td>11/01/11</td>
<td>18400</td>
</tr>
<tr>
<td>11/02/11</td>
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<td>32600</td>
</tr>
<tr>
<td>11/10/11</td>
<td>38000</td>
</tr>
</tbody>
</table>
**Suzie's Escort to Heaven**

- Checklist is essential ~ following the steps may vary
- Do not promise that the patient will not wake up
- Schedule Debrief Meeting soon after case ends ~ edit checklist based on findings from this meeting
- Be flexible
- IDT input by everyone is essential for success
- Daily communication between IDT and afterhours staff important ~ staff emotions can run high
- Broaden the spectrum of medications.
- Realize there is a continuum of healing
RESOURCES

- Hospice and Palliative Care Formulary USA, PalliativeDrugs.com, Nottingham UK, 2006; Drug Protocol for Palliative Sedation

QUESTIONS?
The Elizabeth Hospice

150 W. CREST STREET
ESCONDIDO, CA 92025
(760) 737-2050

SERVING OUR COMMUNITIES AS A NOT-FOR-PROFIT SINCE 1978
Informed Consent/Palliative Sedation

Program Goals: Provide relief for suffering unrelieved by other measures.

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Date                                             Patient or Authorized Representative Signature             Relationship

Date                                             Physician Signature

Patient Name: ________________________________________  Clinical Record #  _____________
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

Timothy W. Kirk, PhD, and Margaret M. Mahon, PhD, RN, FAAN, for the Palliative Sedation Task Force of the National Hospice and Palliative Care Organization Ethics Committee

Department of History & Philosophy (T.W.K.), City University of New York—York College, Jamaica, New York; and School of Nursing (M.M.M.), College of Health & Human Services, George Mason University, Fairfax, Virginia, USA

Introduction

The National Hospice and Palliative Care Organization (NHPCO) endorses the definition of “palliative care” put forth by the National Quality Forum. 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 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. 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.” 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. 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.

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, 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.”

Intolera ble 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. 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.

Intractable suffering is suffering that has not adequately responded to all tried 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
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).”\textsuperscript{5(p229)} 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.\textsuperscript{16}

Refractory suffering is suffering that “cannot be adequately controlled despite aggressive efforts to identify tolerable therapy that does not compromise consciousness.”\textsuperscript{17(p31)} 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.”\textsuperscript{13(p720)} (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.”\textsuperscript{18,19} Although often caused by—or experienced simultaneously with—physical pain, suffering can be a 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.\textsuperscript{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 in the next section, 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.\textsuperscript{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.\textsuperscript{25(p2e2)}
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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{29} 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”\textsuperscript{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.”\textsuperscript{24}\textsuperscript{[\textsuperscript{a}]\textsuperscript{87}} 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.\textsuperscript{30,31}

NHPCO argues that, as physicians are often inaccurate in their prognostication,\textsuperscript{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.\textsuperscript{[54]} 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.\textsuperscript{[34]} Davis\textsuperscript{[35]} 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.\textsuperscript{[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. 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. Rietjens et al. 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 Thorns 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.

Frequency of Use

Palliative sedation should be used rarely. Prevalence of the use of palliative sedation in terminally ill patients has been reported between 1% and 52%, 14,20,22,25 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.

NHPICO 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 NHPICO ethics committee being unable to reach consensus on a recommendation regarding the use of palliative sedation for suffering which 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. In these cases, in addition to a medically led interdisciplinary team with clinical expertise in palliative care, and an individual review of each case, NHPICO 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, NHPICO 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.

Acknowledgments

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References


Palliative Sedation Checklist

☐ RN Visit
    Notify Hospice physician
    Conventional treatment attempted

☐ Aggressive measures fail to provide relief

☐ Care Team including MD, Chaplain, MSW, RNCM meet to discuss optional PS

☐ Interdisciplinary Team and Hospice MD joint visit to discuss palliative sedation, discuss plan of care, risk and benefits

☐ Physician to fully assess previous drug history

☐ Notify primary physician (if any) that palliative sedation is considered

☐ Hospice MD to collaborate with a second Hospice physician regarding use of palliative sedation

☐ CORE IDG (including entire Care Team)

☐ Managers verify staffing availability

☐ Patient or DPOA agree to palliative sedation/consent form signed

☐ Signed DNR verified / Verify copy of power of attorney (if available)

☐ Establish IV access, PICC line preferred

☐ Insert Foley catheter

☐ Palliative sedation to be implemented at home or facility/Crisis care with RN staffing for 24 hours minimum (If in a facility, discuss financial responsibility with patient/family)

☐ Daily Physician Visits
    Review efficacy and goals of treatment as part of physician visit

☐ MSW and Chaplain visits as needed to support caregivers

☐ Daily verbal report between Triage RNs and CC RNs

☐ Adequate medication supply over the weekend

☐ Notify Bereavement Department of initiation of PS case
**Palliative Sedation Medications**

<table>
<thead>
<tr>
<th>Anxiolytic</th>
<th>+/−</th>
<th>Antipsychotic</th>
<th>+/−</th>
<th>Analgesic</th>
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<tbody>
<tr>
<td><strong>Midazolam</strong>&lt;br&gt;1 - 5 mg load IV/SC then &lt;br&gt;0.5 - 1.5 mg/hr IV/SC</td>
<td></td>
<td><strong>Haloperidol</strong>&lt;br&gt;1 mg bolus IV/SC then &lt;br&gt;0.5 - 1 mg/hr IV/SC</td>
<td></td>
<td><strong>Morphine</strong>&lt;br&gt;1 - 5 mg/hr IV/SC titrate to effect* &lt;br&gt;or &lt;br&gt;<strong>Hydromorphone</strong>&lt;br&gt;0.2 - 1 mg/hr IV/SC titrate to effect*</td>
</tr>
<tr>
<td><strong>Lorazepam</strong>&lt;br&gt;0.5 - 1 mg/hr IV/SC</td>
<td></td>
<td><strong>Zaprisadone (Geodon)</strong>&lt;br&gt;5 - 10 mg IM q 2-4 h</td>
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- Goal is relief of refractory symptoms of terminal agitation, resistant delirium, nausea/vomiting, pain or respiratory distress.

- Sedation for agitation or delirium may be reversed if inciting factors mitigated. Sedation for pain or respiratory distress is usually disease related and not reversible.

- Parenteral access is preferred for reliability and predictability of medication dosing. Low flow pumps are preferable and medication concentrations may need to be increased to avoid over hydration.

- If the patient is also delirious and not calmed with anxiolytics a phenothiazine may be added.

- If atropine/hyoscyamine/scopolamine/glycopyrrolate are anticipated for tracheal secretions they should be initiated as soon as tracheal rattle is detected.

Source:<br>Hospice and Palliative Care Formulary USA, Palliativedrugs.com, Nottingham UK, 2006; Drug Protocol for Palliative Sedation
Palliative Sedation

**Purpose:** The purpose of palliative sedation is to relieve suffering from refractory symptoms, but not to hasten death. The intent is the relief of unendurable suffering and not to end the patient’s life.

**Background:** A refractory symptom is one that cannot be adequately controlled despite aggressive efforts to identify a tolerable therapy that does not compromise consciousness. Whenever a patient experiences refractory symptoms, palliative sedation may be considered as an intervention to control unendurable suffering. It may be initiated in a clinical setting or the patient’s home.

**Procedure:**

1. Whenever a patient experiences refractory symptoms, and all conventional treatments have been exhausted and fail to provide relief, palliative sedation may be considered as an intervention to control unendurable suffering. It may be initiated in a clinical setting or the patient’s home.

2. The patient maintains a DNR, FULL NO CODE physician’s order.

3. Sedation need not be requested by the patient and family, but can be suggested by hospice staff as part of the care plan. This procedure is flexible enough to allow for staff to respond to a crisis change in patient’s symptoms on a 24-hour basis.

4. If a staff member feels palliative sedation should be considered, an RN assessment followed by a physician consult should take place prior to discussing with the patient.

5. The decision to initiate palliative sedation must be preceded by a comprehensive interdisciplinary team assessment of the patient and a discussion of treatment expectations and options.

6. All members of the team are essential to the discussion and provision of palliative sedation. A joint visit by the core care team and the hospice physician should occur to discuss the plan of care, risks and benefits.

7. Review by the interdisciplinary team is required to assure the following criteria have been met:
   
   A. Presence of a terminal diagnosis
   B. A do-not-resuscitate (DNR) order
   C. Verify copy of DPOA (if available)
   D. Assessment by hospice physician of previous drug history
E. Exhaustion of all palliative treatments, including treatment for depression, anxiety, delirium, and familial discord

F. Assessment for spiritual issues by a chaplain or clergy member.

8. The patient’s primary care/attending physician, if any, is informed of the decision to initiate palliative sedation. A consultation with a second hospice certified physician must occur and both must agree on the decision to implement palliative sedation.

9. In addition, a CORE IDG discussion is required. Regional managers verify staffing availability.

10. Informed consent is obtained from the patient, or, if lacking capacity, the patient’s designated representative. A discussion of the risks and benefits of palliative sedation will be part of the informed consent process. The written consent for palliative sedation will be obtained by the physician.

11. IV access via PICC line is preferred, if possible. Foley catheter inserted to avoid patient arousal to void.

12. With the initiation of palliative sedation, continuous care registered nursing must be provided for at least 24 hours. A registered nurse will assess the patient closely during the initiation of therapy until the medication(s) is titrated to the desired effect. The registered nurse will monitor and collaborate with the hospice physician for any adverse effect, or change in dosing. Ongoing monitoring will be determined according to the clinical needs of the patient.

13. If patient resides in a facility, financial responsibility for room and board to be clarified with patient/family.

14. Once the patient is sedated, medications are titrated per physician’s order. The goal of palliative sedation is to relieve symptoms by decreasing the level of consciousness. The eyelash reflex is used to assess level of sedation. A soft tactile stroke over a closed eyelid should cause a reduced flicker/reflex in a first stage anesthesia. A lack of flicker (reflex) indicates deep sedation.

15. RN to assure a sufficient supply of medications are present in the home to manage symptoms through the weekend, including boluses and potential increases of the basal rate.

16. Decrease in sedatives will be considered if the patient experiences heavy snoring unusual to baseline or abrupt onset of apnea. Gradual deterioration of respirations is expected in terminal patients and should not alone constitute a reason to decrease sedation.

17. Hospice providers will provide education regarding hydration and nutrition as a separate intervention with the patient and family/DPOA.

18. Sedation will not be attempted solely by increasing opioid dosages, however, opioids will be continued in order to ensure pain management and to prevent opioid withdrawal.

19. Daily physician visits will be made to review the efficacy and goals of the treatment plan.

20. MSW and Chaplain visits as needed to support caregivers should be provided.
21. A debriefing session will be scheduled following the conclusion of the treatment.

Reference:

Medicare CoP: n/a
State Licensure: n/a
Informed Consent/Palliative Sedation

Program Goals: Provide relief for suffering unrelieved by other measures.

Documentation of suffering unrelieved by other measures:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Palliative measures previously attempted and outcome:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

PATIENT _____ HEALTH CARE PROXY/PATIENT REPRESENTATIVE _____ (check one)

( ) Able to respond intelligibly to queries
( ) Able to participate rationally in decision-making
( ) Able to articulate the decision

Information Presented:

( ) Nature and progress of stage of terminal illness (prognosis)
( ) Verified DNR status and expected outcome from proposed Palliative Sedation
( ) Effects limitation, side effects, and risks of the proposed Palliative Sedation

( ) I am aware that Dr. ____________________ agrees with the plan to initiate Palliative Sedation.

With knowledge of the risks discussed by the physician(s), I consent to Palliative Sedation for refractory suffering.

__________________________  ____________________________  ___________________________
Date                                Patient or Authorized Representative Signature           Relationship

__________________________
Date                                Physician Signature

Patient Name: _______________________________  Clinical Record #  ____________

The Elizabeth Hospice

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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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University, Fairfax, Virginia, USA

Introduction

The National Hospice and Palliative Care Organization (NHPCO) endorses the definition of “palliative care” put forth by the National Quality Forum. 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. 5)

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,

This paper was written by Timothy W. Kirk, PhD, and Margaret M. Mahon, PhD, RN, FAAN, on behalf of the Palliative Sedation Task Force of the National Hospice and Palliative Care Organization (NHPCO) Ethics Committee. Members of the Palliative Sedation Task Force were Timothy W. Kirk, PhD (Chair), Kathleen Bliss, MSN, RN, CHA, Pamela Dalinis, MA, BSN, RN, Margaret M. Mahon, PhD, RN, FAAN, Martha McCusker, MD, FACP, W. Brian Guthrie, MD, Marian Silverman, PhD, RN, CHPN, and Joseph Wadas, STL. This paper was approved by the NHPCO Ethics Committee in October 2009 and the NHPCO Board of Directors in December 2009.

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Keywords in italics are defined in the definition section of this paper.

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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. 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.” 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. 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.

**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, 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. 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.

**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.\textsuperscript{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)."\textsuperscript{5(p6229)} 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.\textsuperscript{16}

**Refractory suffering** is suffering that "cannot be adequately controlled despite aggressive efforts to identify tolerable therapy that does not compromise consciousness."\textsuperscript{17(p31)} 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."\textsuperscript{13(p720)} (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.”\textsuperscript{18, 19} Although often caused by—or experienced simultaneously with—physical pain, suffering can be a 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.

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**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.\textsuperscript{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 in the next section, 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, NHPPO recognizes that experts in anesthesiology and in pain medicine have made specific recommendations. NHPPO also recognizes that many of the medications used in palliative sedation can create their own burden and, if administered incorrectly, can even cause death.\textsuperscript{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.\textsuperscript{25(p2)}
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.²⁰,²⁷

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.²⁹ 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 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.²⁰,³¹

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.\(^2\)\(^4\)\(^5\)\(^6\)\(^7\) 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.\(^8\) Davis\(^9\) 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.\(^2\)\(^2\),\(^3\)\(^6\)

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. 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. Rietjens et al. 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 Thorns 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. Frequency of Use

Palliative sedation should be used rarely. Prevalence of the use of palliative sedation in terminally ill patients has been reported between 1% and 52%. 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 which 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. 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.

Acknowledgments

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References


Palliative Sedation Checklist

☐ RN Visit
   Notify Hospice physician
   Conventional treatment attempted

☐ Aggressive measures fail to provide relief

☐ Care Team including MD, Chaplain, MSW, RNCM meet to discuss optional PS

☐ Interdisciplinary Team and Hospice MD joint visit to discuss palliative sedation, discuss plan of care, risk and benefits

☐ Physician to fully assess previous drug history

☐ Notify primary physician (if any) that palliative sedation is considered

☐ Hospice MD to collaborate with a second Hospice physician regarding use of palliative sedation

☐ CORE IDG (including entire Care Team)

☐ Managers verify staffing availability

☐ Patient or DPOA agree to palliative sedation/consent form signed

☐ Signed DNR verified / Verify copy of power of attorney (if available)

☐ Establish IV access, PICC line preferred

☐ Insert Foley catheter

☐ Palliative sedation to be implemented at home or facility/Crisis care with RN staffing for 24 hours minimum (If in a facility, discuss financial responsibility with patient/family)

☐ Daily Physician Visits
   Review efficacy and goals of treatment as part of physician visit

☐ MSW and Chaplain visits as needed to support caregivers

☐ Daily verbal report between Triage RNs and CC RNs

☐ Adequate medication supply over the weekend

☐ Notify Bereavement Department of initiation of PS case
### Palliative Sedation Medications

<table>
<thead>
<tr>
<th>Anxiolytic</th>
<th>Antipsychotic</th>
<th>Analgesic</th>
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</thead>
<tbody>
<tr>
<td>Midazolam 1 - 5 mg load IV/SC then 0.5 - 1.5 mg/hr IV/SC</td>
<td>Haloperidol 1 mg bolus IV/SC then 0.5 - 1 mg/hr IV/SC</td>
<td>Morphine 1 - 5 mg/hr IV/SC titrate to effect*</td>
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<td>or</td>
<td>or</td>
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<tr>
<td>Lorazepam 0.5 - 1 mg/hr IV/SC</td>
<td>Zaprisadone (Geodon) 5 - 10 mg IM q 2-4 h</td>
<td>or</td>
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<tr>
<td></td>
<td></td>
<td>Hydromorphone 0.2 - 1 mg/hr IV/SC titrate to effect*</td>
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- Goal is relief of refractory symptoms of terminal agitation, resistant delirium, nausea/vomiting, pain or respiratory distress.
- Sedation for agitation or delirium may be reversed if inciting factors mitigated. Sedation for pain or respiratory distress is usually disease related and not reversible.
- Parenteral access is preferred for reliability and predictability of medication dosing. Low flow pumps are preferable and medication concentrations may need to be increased to avoid overhydration.
- If the patient is also delirious and not calmed with anxiolytics a phenothiazine may be added.
- If atropine/hyoscyamine/scopolamine/glycopyrrolate are anticipated for tracheal secretions they should be initiated as soon as tracheal rattle is detected.

Source:
Hospice and Palliative Care Formulary USA, Palliativedrugs.com, Nottingham UK, 2006; Drug Protocol for Palliative Sedation
Palliative Sedation

**Purpose:** The purpose of palliative sedation is to relieve suffering from refractory symptoms, but not to hasten death. The intent is the relief of unendurable suffering and not to end the patient’s life.

**Background:** A refractory symptom is one that cannot be adequately controlled despite aggressive efforts to identify a tolerable therapy that does not compromise consciousness. Whenever a patient experiences refractory symptoms, palliative sedation may be considered as an intervention to control unendurable suffering. It may be initiated in a clinical setting or the patient’s home.

**Procedure:**
1. Whenever a patient experiences refractory symptoms, and all conventional treatments have been exhausted and fail to provide relief, palliative sedation may be considered as an intervention to control unendurable suffering. It may be initiated in a clinical setting or the patient’s home.
2. The patient maintains a DNR, FULL NO CODE physician’s order.
3. Sedation need not be requested by the patient and family, but can be suggested by hospice staff as part of the care plan. This procedure is flexible enough to allow for staff to respond to a crisis change in patient’s symptoms on a 24-hour basis.
4. If a staff member feels palliative sedation should be considered, an RN assessment followed by a physician consult should take place prior to discussing with the patient.
5. The decision to initiate palliative sedation must be preceded by a comprehensive interdisciplinary team assessment of the patient and a discussion of treatment expectations and options.
6. All members of the team are essential to the discussion and provision of palliative sedation. A joint visit by the core care team and the hospice physician should occur to discuss the plan of care, risks and benefits.
7. Review by the interdisciplinary team is required to assure the following criteria have been met:
   A. Presence of a terminal diagnosis
   B. A do-not-resuscitate (DNR) order
   C. Verify copy of DPOA (if available)
   D. Assessment by hospice physician of previous drug history
E. Exhaustion of all palliative treatments, including treatment for depression, anxiety, delirium, and familial discord

F. Assessment for spiritual issues by a chaplain or clergy member.

8. The patient’s primary care/attending physician, if any, is informed of the decision to initiate palliative sedation. A consultation with a second hospice certified physician must occur and both must agree on the decision to implement palliative sedation.

9. In addition, a CORE IDG discussion is required. Regional managers verify staffing availability.

10. Informed consent is obtained from the patient, or, if lacking capacity, the patient’s designated representative. A discussion of the risks and benefits of palliative sedation will be part of the informed consent process. The written consent for palliative sedation will be obtained by the physician.

11. IV access via PICC line is preferred, if possible. Foley catheter inserted to avoid patient arousal to void.

12. With the initiation of palliative sedation, continuous care registered nursing must be provided for at least 24 hours. A registered nurse will assess the patient closely during the initiation of therapy until the medication(s) is titrated to the desired effect. The registered nurse will monitor and collaborate with the hospice physician for any adverse effect, or change in dosing. Ongoing monitoring will be determined according to the clinical needs of the patient.

13. If patient resides in a facility, financial responsibility for room and board to be clarified with patient/family.

14. Once the patient is sedated, medications are titrated per physician's order. The goal of palliative sedation is to relieve symptoms by decreasing the level of consciousness. The eyelash reflex is used to assess level of sedation. A soft tactile stroke over a closed eyelid should cause a reduced flicker/reflex in a first stage anesthesia. A lack of flicker (reflex) indicates deep sedation.

15. RN to assure a sufficient supply of medications are present in the home to manage symptoms through the weekend, including boluses and potential increases of the basal rate.

16. Decrease in sedatives will be considered if the patient experiences heavy snoring unusual to baseline or abrupt onset of apnea. Gradual deterioration of respirations is expected in terminal patients and should not alone constitute a reason to decrease sedation.

17. Hospice providers will provide education regarding hydration and nutrition as a separate intervention with the patient and family/DPOA.

18. Sedation will not be attempted solely by increasing opioid dosages, however, opioids will be continued in order to ensure pain management and to prevent opioid withdrawal.

19. Daily physician visits will be made to review the efficacy and goals of the treatment plan.

20. MSW and Chaplain visits as needed to support caregivers should be provided.
21. A debriefing session will be scheduled following the conclusion of the treatment.

**Reference:**

- Medicare CoP: n/a
- State Licensure: n/a