



## **HPNA Position Statement**

### **Palliative Sedation**

It is the position of the Hospice and Palliative Nurses Association (HPNA) that:

- Palliative care, including hospice care that includes aggressive and comprehensive symptom management, is an important resource.
- Palliative sedation can be used for imminently dying patients to manage refractory symptoms unrelieved by optimal palliative care.
- Hospice and palliative nurses must understand palliative sedation, and its ethical and legal justifications for use.

#### **Education**

- Hospice and palliative care nurses must possess sufficient knowledge about the issues surrounding the use of palliative sedation to inform patients, families, and other healthcare providers in making decisions about its use.

#### **Clinical Practice**

- Interventions and appropriate escalation of analgesic and/or sedative doses should be used to relieve suffering without the intention of hastening death.
- Optimal care includes consultation with palliative care specialists prior to the decision to implement palliative sedation to ensure the appropriateness of this intervention. Hospice and palliative nurses should consult with interdisciplinary colleagues including psychiatrists, psychologists, ethicists, chaplains, social workers, and pharmacists to ensure all potential treatment options are explored and implemented, and that no further options exist except palliative sedation.
- A nurse can object to the use of palliative sedation and has the right to transfer care. However, those nurses who choose not to participate in palliative sedation are directed to continue to provide care until responsibility for care is transferred to an equally competent colleague to avoid abandonment of the patient.

#### **Policy**

- Nurses must participate in the development of policies and procedures to treat intractable symptoms.
- It is the nurse's role to disseminate information about palliative sedation and how it differs from hastening death or assisted suicide.
- Informed consent must be used for palliative sedation. Patients who lack decision-making capacity and who do not have a previously designated surrogate decision-maker should have such a person named in accordance to state, local, and institutional regulations who can assist with informed consent for palliative sedation.



- Palliative sedation can be used for children. Parents/guardians have the legal authority to make decisions regarding treatment for their children if the child is under the age of 18 and are considered to have their child's best interest at heart, thus palliative sedation may be part of a conversation with pediatric patients. However, the child's views and preferences for medical care, including assent and refusal for treatment (when developmentally appropriate), is documented and given appropriate weight in decision-making about palliative sedation. When the child's wishes differ from those of the adult decision-maker, appropriate professional staff members are available to assist the child as well as the family.<sup>24</sup>

### **Leadership**

- It is the role of palliative nurses to promote public understanding of the difference between withholding/withdrawing life-sustaining therapies and euthanasia and assisted suicide.<sup>13,19</sup>
- Palliative nurses must support patients, families, and colleagues in the decision-making process of palliative sedations.
- It is the role of palliative nurses to facilitate the decision-making process and advocate for care that is consistent with the stated wishes of the patient and their surrogates for which palliative sedation may be appropriate to treat suffering, promote comfort, and optimize dignity.

### **Background**

Patients at the end of life may suffer an array of physical and psychological symptoms and subsequent existential distress that, in most cases, can be prevented or relieved through optimal palliative care.<sup>1,2</sup> Situations could arise when conscious patients who are imminently dying may experience intractable symptoms that are intolerable and are unrelieved by expert palliative care, and in these circumstances, palliative sedation may be utilized to reduce suffering.

Palliative sedation is generally defined as the administration of medications in doses that induce unconsciousness while relieving distress from intractable pain and symptoms.<sup>2</sup> With the intent to relieve suffering through sedation, it is very distinct from euthanasia, which does hasten death.

While there is no universally accepted definition, palliative sedation is commonly understood as the controlled and monitored use of nonopioid medications with the intention of reducing the patient's level of consciousness for relief of refractory and unendurable symptoms. Previously called terminal sedation, the name was modified to more accurately reflect the intent and application of its use—to palliate the patient's experience of symptoms rather than to cause or hasten death.<sup>2</sup> Other terms include total sedation, sedation for intractable symptoms at end of life, continuous sedation, or prolonged sedation.<sup>3-5</sup> Palliative sedation is distinct from conscious sedation for procedures, respite sedation, and sedation resulting from medications alone.<sup>5,6</sup> The



prevalence of palliative sedation in clinical practice is unknown, with reports varying widely, ranging from 1.33% to 51% of dying patients.<sup>7,8,9</sup>

The use of medication to promote comfort and relieve pain in dying patients is supported by the American Nurses Association's *Code of Ethics for Nurses with Interpretive Statements*, which states, "the nurse should provide interventions to relieve pain and other symptoms in the dying patient even if those interventions entail the risk of hastening death. However, nurses may not act with the sole intent to end a patient's life even if motivated by compassion, respect for patient autonomy, and quality of life considerations."<sup>10(pp8)</sup>

The practice of palliative sedation is grounded in the precepts of dignity, respect for autonomy, beneficence, fidelity, and nonmaleficence.<sup>11,12</sup> These principles support the right of the individual to make healthcare decisions based on personal values and quality of life considerations,<sup>11</sup> and reinforce the responsibility of clinicians to provide humane and compassionate care that is consistent with professional and societal norms.

Additionally, the principle of double effect provides justification based on the proportionality of benefit and harm (i.e., the intent to relieve pain and symptom vs. hasten death). The intent of palliative sedation is to relieve suffering in dying patients, but not to deliberately hasten death. This is very distinct from euthanasia, assisted suicide, or any intervention such as inappropriate escalation of analgesic or sedative doses where the intent is solely to hasten the patient's death.<sup>10,13,14</sup> The practice of palliative sedation is supported by the 1997 U.S. Supreme Court decisions in *Vacco v. Quill*<sup>15</sup> and *Washington v. Glucksberg*,<sup>16</sup> which state a patient who is suffering from a terminal illness and who is experiencing great pain has no legal barriers to obtaining medication to alleviate that suffering, even to the point of unintentionally causing unconsciousness and hastening death.

The process of instituting palliative sedation first requires interdisciplinary assessment of the patient to determine the refractory nature of their symptoms and subsequent suffering.<sup>17</sup> Communication with the patient, family/significant other/surrogate decision-maker, and other healthcare providers about the use of palliative sedation is essential. Collaboration with the interdisciplinary team not only validates the appropriateness of palliative sedation and facilitates the informed-consent process, but also reduces the emotional burden for healthcare providers.<sup>8,9,18,19</sup>

Palliative sedation requires comfort to be the priority goal of care.<sup>5,8,9,13</sup> The process focuses on the use of sedative medications and the concurrent use of analgesic medications for appropriate pain control to treat refractory pain or symptoms. The use of cardiopulmonary resuscitation is generally viewed as inconsistent with palliative sedation, however, decisions to withhold/withdraw other life-sustaining therapies are best made separately from the decision to use palliative sedation.<sup>20</sup> Such discussions should occur prior to initiating palliative sedation.



Much like other palliative procedures (e.g. conscious sedation, receiving certain medications), palliative sedation requires formal informed consent to occur.

Patients and families should receive a full explanation of the goal of palliative sedation, what it is and isn't, medications used, and the expected outcomes.<sup>21</sup> The possibility of death should be discussed and the informed process should be documented.

Finally, it is imperative that when palliative sedation is offered as part of the plan of care, organizational policies and procedures are in place to establish a consistent and agreed-upon process. At a minimum, these policies and procedures should include the roles of the physician, the bedside registered nurse (RN), the advanced practice registered nurse (APRN), the pharmacist, and the requirement of a palliative care consultation or a pain consultation. Hospice and palliative RNs and APRNs should understand their scope of practice within their organization and state in terms of care delivery.<sup>10,13,19,22</sup>

Most importantly, there should be clear documentation during the use palliative sedation as a last-resort therapy including pain and symptoms that are intractable; previously tried and failed treatments (e.g., medications and interventions); multidisciplinary consultations (e.g., chaplaincy, psychiatry, pain services) to help manage pain and symptoms; elements of informed consent; the plan for palliative sedation focusing on the medication; and the actual process that occurred including which medication was used, the dosage, the patient's response to medication, and the family coping with the process.<sup>8,9,23</sup>

### **Definition of Terms**

**Autonomy:** A multidimensional ethical concept. It is the right of a capable person to decide their own course of action based on personal values and goals of life. Self-determination is a legal right.<sup>11,21</sup>

**Beneficence:** An ethical duty to act to benefit the recipient of care. It is based on the patient's perception of benefit and relates to promoting well-being.<sup>11,21</sup>

**Dignity or respect for person:** A fundamental ethical principle. Dignity is the quality or state of being honored and valued. Respecting the body, values, beliefs, goals, privacy, actions, and priorities of an autonomous adult preserves their dignity. This is a broader concept than autonomy.<sup>9,11,21</sup>

**Fidelity:** The ethical imperative to keep promises. For healthcare providers, fidelity includes the promise not to abandon the patient.<sup>11</sup>

**Imminent death:** Refers to death that is expected to occur within hours to days based on the person's current condition, progression of disease, and symptom constellation.<sup>25</sup>



**Informed consent:** A tenet of autonomy. To make an autonomous decision, the person must have all sufficient and relevant information as well as decision-making capacity. Capacity requires that the person understand the consequences of the decision; has sufficient information and understanding about the treatment, likely outcomes, and foreseeable consequences; and be able to make the decision without coercion.<sup>11,21</sup>

**Intent:** The purpose or state of mind at the time of an action. Intent of the patient/surrogate decision-maker and healthcare providers is a critical issue in ethical decision-making concerning palliative sedation. Relief of suffering, not hastening or causing death, is the intent of palliative sedation.<sup>6,11</sup>

**Nonmaleficence:** The ethical duty to do no harm. When beneficence conflicts with nonmaleficence, there is a greater duty to avoid inflicting harm.<sup>11</sup>

**Palliative sedation:** "When terminally ill, conscious patients experience intolerable symptoms that cannot be relieved by expert palliative care, palliative sedation involves administering sedatives and nonopioid medications to relieve suffering in doses that may induce unconsciousness, but not death"<sup>1(pp583)</sup>

**Principle of double effect:** A bioethical concept that provides moral justification for an action that has two foreseen effects: one good and one bad. The key factor is the intent of the person performing the act. If the intent is good (e.g., relief of pain and suffering) then the act is morally justifiable even if it causes a foreseeable but unintended result (e.g., hastening of death).<sup>11</sup>

**Refractory symptom:** A symptom that cannot be adequately controlled in a tolerable time frame or at a tolerable level despite aggressive use of usual therapies and seems unlikely to be adequately controlled by further invasive or noninvasive therapies without excessive or intolerable acute or chronic side effects/complications.<sup>18</sup>

**Respite sedation:** The use of sedation for a brief, planned period to provide symptom relief and rest with the goal of returning to consciousness and pursuing future therapeutic and/or palliative therapies.<sup>16,22</sup>

**Suffering:** An individual and private experience characterized by a state of severe distress induced by loss of intactness of person or threat that the person believes will result in loss of their intactness related to physical pain, unrelieved symptoms, spiritual distress, depression, or multiple losses.<sup>17,26</sup>

**Surrogate decision-maker:** Someone appointed by the patient to make healthcare decisions. The role of the surrogate decision-maker is to make decisions for the patient based on the patient's preferences and previously expressed wishes.<sup>27</sup>



**Surrogate decision-making:** Utilized if the person lacks capacity to make an informed choice. Surrogate or proxy decisions should be based on one or more of the following: written advance directives; substituted judgment based on subjective knowledge of the person's values, views on quality of life, and goals; or the best interest of the person whose wishes and values are unknown and based on weighing benefits/burden of recommended actions.<sup>3,11,21</sup>

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