

## HPNA Position Statement Palliative Sedation

### 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> There may be situations when conscious patients who are imminently dying may experience intractable symptoms that are intolerable and are unrelieved by expert palliative care. 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 the 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 non-opioid medications with the intention of reducing the patient's level of consciousness for relief of awareness of refractory and unendurable symptoms. Previously termed 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 the patient's 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, as well as 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 ANA's *Code of Ethics for Nurses*, which states that "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,p.8</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> The principles reinforce the responsibility of clinicians to provide humane and compassionate care that is consistent with professional and societal norms.

In addition, the principle of double effect provides justification in which the process is based on the intended outcome of pain and symptom relief and the proportionality of benefit and harm. 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 his/her 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 the healthcare providers.<sup>8,9,18,19</sup>

The use of palliative sedation requires that comfort 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 pain control as appropriate to treat refractory pain or symptoms. The use of cardiopulmonary resuscitation is generally viewed as inconsistent with palliative sedation. However, conversations about decisions to withhold or withdraw other life-sustaining therapies including artificial hydration and nutrition are best made separately from the decision to use palliative sedation.<sup>20</sup> Such discussions should be held prior to initiating palliative sedation.

Since palliative sedation is a palliative procedure, much like conscious sedation or receiving certain medications, the formal informed consent is imperative. 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. 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, the advanced practice registered nurse, the pharmacist and the requirement of a palliative care consultation or a pain consultation. Hospice and palliative registered nurses and advanced practice registered nurses should understand their scope of practice within their organization and state in terms of their care delivery.<sup>10,13,19,22</sup>

Most important, there should be clear documentation of palliative sedation as a therapy including: pain and symptoms that are intractable; previously tried and failed treatments (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 finally, 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>

## **Position Statement**

The Hospice and Palliative Nurses Association:

- Affirms the value of palliative care, including hospice care that includes aggressive and comprehensive symptom management.
- Affirms the use of palliative sedation in imminently dying patients to manage refractory symptoms unrelieved by optimal palliative care.
- Asserts that hospice and palliative nurses must understand palliative sedation, and its ethical and legal justifications for use.

### **Education**

- Asserts that 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**

- Supports the use of interventions and appropriate escalation of analgesic and/or sedative doses to relieve suffering without the intention of hastening death.
- Affirms that optimal care includes consultation with palliative care specialists prior to the decision to implement palliative sedation to ensure the appropriateness of this intervention. In addition, consultation with interdisciplinary colleagues including psychiatrists, psychologists, ethicists, chaplains, social workers, and pharmacists should be made to ensure all potential treatment options are explored and implemented, and that no further options exist except palliative sedation.
- Allows for a nurse's conscientious objection and upholds the nurse's 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

- Promotes nurse participation in the development of policies and procedures to treat intractable symptoms.
- Supports the nurse role in disseminating information about palliative sedation and how it differs from hastening death or assisted death.
- Promotes informed consent 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.
- Affirms palliative sedation for children. Parents/guardians have legal authority to make decisions regarding treatment for their children if the child is under the age of 18, and the parents are considered to have their child's best interest at heart. 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

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

#### **Definition of Terms** (Refer to the HPNA Definition of Terms Document)

*Autonomy*: a multidimensional ethical concept. It is the right of a capable person to decide his/her 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, state, of being honored or 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>

*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>

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

*Informed consent:* a tenet of autonomy. To make an autonomous decision, the person must have sufficient and relevant information as well as capacity to make the decision. Capacity requires that the person understands 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>

*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>

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

*Proxy decision making:* allowed if the person lacks capacity to make an informed choice. Proxy or surrogate decisions should be based on one or more of the following: written advance directives; substituted judgment, which is based on subjective knowledge of the person's values, views on quality of life, 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>

*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 non-opioid medications to relieve suffering in doses that may induce unconsciousness, but not death"<sup>1</sup>, p. 583

*Refractory symptom:* one 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 his/her intactness related to physical pain, unrelieved symptoms, spiritual distress, depression, or multiple losses.<sup>17,26</sup>

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