

# American Society for Pain Management Nursing Position Statement: Pain Management at the End of Life

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## ■ ABSTRACT:

**Pain at the end of life continues to be of great concern as it may be unrecognized or untreated. While nurses have an ethical obligation to reduce suffering at the end of life, barriers remain regarding appropriate and adequate pain management at the end of life. This position statement from the American Society for Pain Management Nursing contains recommendations for nurses, prescribers, and institutions that would improve pain management for this vulnerable population.**

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## POSITION STATEMENT

The American Society for Pain Management Nursing (ASPMN) holds the position that nurses and other health care providers must advocate for optimal pain and symptom management to alleviate suffering for every patient receiving end-of-life care.

## BACKGROUND

The prevalence of pain at the end of life had been estimated at 51% by Sykes and Thorns (2003). Smith et al. (2010) found that in the last month of life, the prevalence of pain was 46% on average. Among patients with arthritis, 60% experienced pain in their last month of life. A meta-analysis of 52 studies spanning 40 years, found that 64% of patients with advanced cancer have pain. One third of all patients in the reviewed studies rated their pain as moderate or severe (Van den Beuken-Van Everdingen et al., 2007). In most cases, the array of symptoms and existential distress felt by patients can be prevented or relieved through optimal end-of-life care (Hospice and Palliative Care Nursing

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Organization [HPNA], 2008). The American Nurses Association's (ANA) Code of Ethics (2001) affirms the value of end-of-life care that includes aggressive and comprehensive symptom management.

"Nurses should be competent in the care of patients throughout the continuum of life. This includes the obligation for nurses to help manage pain and other distressing symptoms for patients with serious or life-limiting illness..." (ANA, 2010, p.7). Therefore, nurses must use effective doses of medications prescribed for symptom control, and nurses must advocate on behalf of the patient when prescribed medication is not managing pain and other distressing symptoms.

Effective pain and symptom management at the end of life increases quality of life and may prolong life rather than accelerate death. A review of five studies found there is no evidence that initiation of treatment or increases in dose of opioids or sedatives is associated with precipitation of death (Sykes & Thorns, 2003). A retrospective study of patients cared for at home found the use of opioids, even high-dose opioids or escalating doses, did not shorten survival (Bengochea, Gutierrez, Vrotsou, Oinaindia, & Lopez, 2010).

For the patient dying in a critical care setting, uncertainty surrounds the care goals. Critical care nurses and physicians may be inadequately prepared to deliver palliative care for the critically ill geriatric patient. Many clinicians have felt that overtreatment occurs when hope for improvement diminishes (Dawson, 2008).

Worry about the possibility of hastening death has led some clinicians and ethicists to use the doctrine of double effect to defend or justify the use of opioids in palliative care. In brief, the doctrine states that an action that causes a serious adverse effect that has been foreseen—including death—may be morally justified if the intention behind the action was to do good (Bengochea, et al., 2010). But Sykes and Thorns (2003) would argue that the doctrine of double effect is not needed, because their studies found that analgesic medications did not hasten death. Although the doctrine of double effect is meant to provide justification for use of aggressive symptom management measures, it may have the reverse effect of engendering a reluctance to use medication to secure comfort and may result in failure to provide adequate relief to a vulnerable group of patients (Sykes & Thorns, 2003). The increasing titration of medication to achieve adequate symptom control is ethically justified (ANA, 2003, p.1).

Many children with life-threatening illnesses experience pain at the end of life. In the Wolfe, Grier, and Klar (2000) study of children who died of cancer, more than 80% experienced pain, yet only 27% were able to achieve pain relief. In the United Kingdom,

a study of 185 children and adolescents receiving treatment for progressive malignant disease reported that pain was a problem for 91.5% of the children; the patients with solid tumors reported the worst pain (Goldman, Hewitt, Collins, Childs & Hain, 2006). Under-treatment of pain is more common in individuals who are not able to speak for themselves, particularly infants and children, and those who are developmentally or cognitively impaired (HPNA, 2008).

Life expectancy is influenced by advances in medicine and technology. One in five United States citizens will be considered elderly by 2030. In 2000, the United States census reported 4.2 million citizens older than 85 years old. By 2020, this group is expected to increase to 7 million (Kelly, 2010). Because persons are living longer with chronic, serious medical conditions, it is expected that the number of persons residing in long-term care facilities will increase. The challenges in long-term care include high prevalence of untreated pain, lack of consistent assessment of pain in persons with cognitive impairment, as well as the lack of recognition of the meaning of behaviors. Health care professionals have an obligation to provide appropriate pain management in this population. Coordination of pain care is absolutely critical to avoid the duplication that can result when several physicians prescribe pain medications, or the neglect that can occur when one physician erroneously assumes that another physician is managing the patient's pain (Reid, 2010).

### Barriers to Care

Barriers to optimal pain management at the end of life come in many forms (Grégoire & Frager, 2006). Although divided into three major categories, the items are not exclusive to just one group:

#### *Patient and Family.*

- Denial by the patient and/or family, causally linking pain as a sign of deterioration.
- Fear that increasing pain is a herald of disease progression.
- Patients' and families' belief that pain is a natural part of illness and cannot be relieved.
- Fear of addiction and abuse.

#### *Health Care Providers.*

- Nonrecognition of the pain, including denial of its presence.
- Nonrecognition of the global nature of pain, including psychological, social, and cultural aspects.
- Fear of doing harm, causing adverse effects, and/or tolerance to opioid effectiveness.
- Fear of diversion.

- Prescriber hubris—when a prescriber chooses not to ask for assistance from pain specialists.
- Exclusion of effective concurrent nonpharmacological measures.

### **Health Care System.**

- Restrictive formularies or cost prohibitions which prevent appropriate treatment.

## **DEFINITIONS**

### **End-of-Life Care**

*“End-of-life care* is the term used to describe the support and health care given during the time surrounding death. Such care does not happen in the moments before breathing finally stops and a heart ceases to beat. At the end of life, each story is different. Death comes suddenly, or a person lingers, gradually failing. An older person is often living, and dying, with one or more chronic illnesses and needs care for days, weeks, and sometimes even months” (National Institute for Aging, 2010).

### **Palliative Care**

A broad term that describes a model of care for the ill, specializing in the relief of the symptoms and stress of serious illness (Coyne, Bobb, & Drew, 2010).

## **ETHICAL CONSIDERATIONS**

Nurses individually and collectively have an obligation to provide comprehensive and compassionate end-of-life care, which includes the promotion of comfort, the relief of pain, and at times, forgoing life-sustaining treatments (ANA, 2001). The ethical tenets of beneficence, nonmaleficence, autonomy, and justice that govern practice continue to guide end-of-life care. Pain at the end of life can be from many sources, and those who are dying deserve to have pain and other symptoms relieved in accordance with their goals and within professional standards of practice. Beneficence (the duty to benefit another) requires nurses to manage pain and provide compassionate care. Non-maleficence (the duty to do no harm) reminds us that acute pain is a warning signal and that unrelieved pain is physically and psychologically harmful. It is also our responsibility not to inflict pain and suffering. As we have these “duties” to the patient, pain relief becomes a patient right (Brennan, Carr, & Cousins, 2007). Patients have the right to be given all the information necessary to make an informed decision and participate in their pain management. Veracity (truth-telling) is the basis for therapeutic relationships. Autonomy along with veracity means the patient and/or the family has

the right to self-determination. (Brown & Bennett, 2010). The Western value of autonomy can be destroyed by the presence of severe unrelieved pain. A patient suffering such pain can often think of nothing except relief and will agree to anything that will provide it. For such patients, truly free and informed consent may be an illusion (Post, Blustein, Gorden, & Dubler, 1996). Justice mandates that everyone have access to pain management.

## **RECOMMENDATIONS FOR NURSES, PRESCRIBERS, AND INSTITUTIONS**

### **Clinical Care**

- Evidence based education for health care providers that leads to improved pain management for patients at end of life.
- Accountability of all health care professionals to support the patient’s wishes and goals.
- Emphasis on effective pain management plans and outcomes.

### **Education**

- Education that pain management is a core health care value and a human right.
- Recognition that all pain is worthy of treatment.
- Education for the public that leads to an understanding of the barriers to pain management at end of life, the harmful effects of pain, and the importance of appropriate pain management.

### **Accessibility**

- Accessibility to the pharmacological and nonpharmacological treatments that are most effective for each patient.
- Accessibility to advanced technology for pain and symptom relief, when indicated.
- Appropriate methods to decrease legal, legislative, and health care reimbursement obstacles.

### **Research**

- Continued research in pain and symptom management.

## **SUMMARY**

Few things we do for patients are more fundamental to the quality of life than relieving pain, especially at the end of life. As nurses, we must continuously advocate for humane and dignified care, promoting ethical, effective pain and symptom management without exception.

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