



Position Statement

Pain Management at the End of Life

*Patrick Coyne, MSN, RN
Carol Mulvenon, APRN, ACHPN
Judith A. Paice, PhD, RN*

Abstract

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

The American Society for Pain Management Nursing and Hospice and Palliative Nurses Association hold the position that nurses and other health care providers must advocate for effective, efficient, and safe pain and symptom management to alleviate suffering for every patient receiving end-of-life care regardless of their age, diseases, history of substance misuse, or site of care. This position statement is directed to the special needs of those individuals with a serious illness and a prognosis of days to months. Other guidelines are available to direct care for those receiving active treatment or those who are long-term survivors (Chou et al., 2009; Dowell, Haegerich, & Chou, 2016; Paice et al., 2016; Ripamonti, Santini, Maranzano, Berti, & Roila, 2012; Swarm et al., 2013). In addition to the recommendations provided in this position statement, the authors endorse early care integration with interdisciplinary palliative care teams and referral to hospice when appropriate (Ferrell et al., 2017).

Background

The prevalence of pain toward the end of life remains unacceptably high. In a recent study of elderly nursing home residents enrolled in hospice, the prevalence of pain was close to 60% (Hunnicut, Tjia, & Lapane, 2017). 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.,

2007b). In individuals for whom curative or palliative chemotherapy was no longer feasible, the prevalence of cancer pain increased to 75% (van den Beuken-van Everdingen et al., 2007a). In a systematic review of the prevalence of symptoms at the end of life, the overall prevalence of pain was identified as 52.4% (Kehl & Kowalkowski, 2013). A consecutive cohort study to describe both intensity and prevalence of symptoms in 18,975 patients imminently dying in either a palliative care unit (70%), in an acute hospital with palliative care support (8.7%), or at home (8.7%) found that although more than half of the patients were not experiencing distressing symptoms, of those patients who did have symptoms, 22.2% identified pain as problematic, and 4.2% reported severe pain (Clark et al., 2016).

To examine the definition of a good death that includes perspectives from patients, family members, and health care providers, a literature review of published studies revealed that an essential core of a good death as identified by 81% of respondents was “pain-free status” (Meier et al., 2016). Similarly, recent systematic reviews were conducted with the aim of determining the most important elements of end of life care identified by patients and their families dying in the hospital. Expert care, which includes management of pain and other symptoms, was identified as one of the essential end-of-life care domains (Virdun, Lockett, Davidson, & Phillips, 2015; Virdun, Lockett, Lorenz, Davidson, & Phillips, 2017).

In most cases, the array of symptoms and existential distress felt by patients with advanced disease can be prevented or relieved through optimal care. However, in a study employing interviews with a bereaved family member or friend of the decedent, these loved ones reported that the patient experienced unmet need for pain management during the end-of-life period (25.2%) (Teno, Freedman, Kasper, Gozalo, & Mor, 2015). This finding and many other studies reinforce the ongoing need to improve the management of pain for people at the end of life (Ziegler, Mulvey, Blenkinsopp, Petty, & Bennett, 2016).

Effective pain and symptom management at the end of life increases quality of life and may prolong life rather than accelerate death (Sutradhar et al., 2014). 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 that the use of opioids, even high-dose opioids or escalating doses, did not shorten survival (Bengoechea, Gutierrez, Vrotsou, Onaindia, & Lopez, 2010). Despite this evidence to the contrary, nurses continue to identify the use of opioids in managing symptoms as one of the ethical dilemmas they face (Cheon, Coyle, Wiegand, & Welsh, 2015). In a study to explore the perceptions of nurses regarding medication use at the end-of-life, they reported hastening death and the potential to decrease respirations as their primary fears (Howes, 2015).

Nurses have an ethical responsibility to provide clinically excellent care to address a patient’s pain. Clinically excellent pain management considers

clinical indications, mutual identification of goals for pain management, interprofessional collaboration, and awareness of professional standards for the assessment and management of different types of pain.” (ANA Position Statement The Ethical Responsibility to Manage Pain and Suffering—Draft Statement) (American Nurses Association, 2017)

Therefore, nurses must use evidence-based, 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. Additionally, nurses must advocate for nonpharmacologic therapies, including psychological approaches, physical measures, integrative therapies, and interventional techniques, when appropriate.

To provide clinically excellent care, nurses must be aware of the barriers to assessment and treatment of pain. Undertreatment 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 (Herr, Coyne, McCaffery, Manworren, & Merkel, 2011). Other groups at risk for undertreatment include the elderly, those with a history of substance use disorder, those with limited social and economic resources, and those who speak a language different from that of their health care professional (Greco et al., 2014; Oliver et al., 2012; Paice & Von Roenn, 2014).

Barriers to Care

Barriers to optimal pain management at the end of life come in many forms (Kwon, 2014; White, Coyne, & White, 2012). The presence of these barriers has been associated with less effective pain control (Gunnarsdottir et al., 2017; Mayahara, Foreman, Wilbur, Paice, & Fogg, 2015). 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
- Stoicism
- Cognitive and affective factors
- Fear of addiction and abuse

Health Care Providers

- Inadequate assessment of pain, including denial of its presence and not utilizing an assessment scale designed for the special needs of each patient when indicated
- Lack of recognition of the global nature of pain, including psychological, social, cultural, and spiritual aspects

- Fear of doing harm, causing adverse effects, and/or tolerance to opioid effectiveness
- Fear of diversion
- Fear of addiction
- Fear of legal issues
- Prescriber hubris—when a prescriber chooses not to ask for assistance from pain or palliative care specialists
- Exclusion of effective concurrent nonpharmacological measures

Health Care System

- Restrictive formularies, limited access to opioids, or cost prohibitions that prevent appropriate treatment
- Limited insurance coverage for many effective treatments such as physical and occupational therapies, as well as mental health counseling
- Lack of availability of pain and palliative care specialists
- Lack of support for adequate pain education and resources for challenging pain cases

Definitions

End-of-Life Care – This 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 on Aging, 2017).

Palliative Care – This describes 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 the physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice (National Consensus Project for Quality Palliative Care, 2013).

Barriers to Care

Nurses have an ethical responsibility to relieve pain and suffering (American Nurses Association, May 9, 2017). Nurses caring for patients at the end of life should recognize that the provision of medications to relieve suffering is consistent with accepted ethical and legal principles. Additionally, there must be recognition that the risk of hastening death by the administration of opioids to patients with serious illnesses is minimal, especially when they are provided using established guidelines. 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 with a serious

diagnosis 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. Nonmaleficence (the duty to do no harm) reminds us that unrelieved pain is physically and psychologically harmful. It is also our responsibility to provide safe and effective pain care. Autonomy means the patient and/or the family has the right to self-determination. To support their autonomy, patients and family members must be given all the information necessary to make an informed decision and participate in their pain management. Justice mandates that everyone have equal and fair 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
- Awareness of the essential role of comprehensive and ongoing pain and symptom management in all patients and, in particular, the patient who is nonverbal during the dying phase
- Accountability of all health care professionals to support the patient's wishes and goals
- Emphasis on effective, efficient, and safe pain management plans and outcomes that are derived from a comprehensive assessment.

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
- Education that the national response to the opioid crisis does not negate the ethical responsibility to relieve pain and suffering.

Accessibility

- Accessibility to the pharmacological and nonpharmacological treatments that are most effective for each patient
- Accessibility to pain and palliative care specialists for pain and symptom relief, when indicated
- Accessibility to hospice services when appropriate
- Appropriate methods to decrease legal, legislative, regulatory, and health care reimbursement obstacles
- Referral and coordination with addiction specialists when there is a risk for substance misuse

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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Approved by the Hospice and Palliative Nurses Association and the
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