



Managing Pain in Patients at End of Life

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Pain management in end-of-life care presents a unique set of opportunities for patients and physicians. Physicians will encounter patients at the end of life regardless of type of specialty practice. Symptom relief is the concern of all physicians. Knowledge of “total pain” concepts along with basic end-of-life pain management offers much to patients and their families. Osteopathic principles and treatment philosophy complement quality pain management in end-of-life care. Physicians providing supportive care can assist patients and their families with comfort at the end of life. Good pain management at the end of life enhances the patient-physician relationship.

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Awareness of basic tenets of pain management and access to practical references allow physicians to care effectively for their patients at the end of life. Pain management for these patients is commonly viewed in terms of anatomy, pathophysiology, and pharmacology. At any time during life, an event can stimulate nociceptors to transmit information that the central nervous system will perceive as pain;

this nociceptive mechanism of pain is well accepted.¹ Medical treatment of patients with such pain focuses on amelioration of acute symptoms.

Even before end of life, nearly half of patients with cancer report moderate to severe pain; up to 30% report the pain as severe; and an estimated 25% will die in pain. Persons with other noncancer diagnoses also report clinically significant pain.² Dr Cicely Saunders, founder of modern hospice care, conceptualized pain associated with the dying process as “total pain.”²

Total pain is the sum of four components: physical noxious stimuli, affect or emotional discomfort, interpersonal conflicts, and nonacceptance of one’s own dying. (Figure 1). These four components may individually or in combination affect patients’ perception of their total pain

(Figure 2).^{3(p17)} Lack of physicians’ understanding of the influence of each of these four components may result in less-than-optimal pain management at the end of life.²

The “gold standard” of pain management is constant assessment. Pain is whatever the patient says it is. Simply asking patients about such discomfort is the best way to obtain this information.^{4(p301)} Patients describe nonphysical components of pain as “discomfort.” Byock⁵ wrote that in dying persons, pain is never purely physical. Events related to when and how they will eventually die influence their pain. These issues include being abandoned; becoming undignified in terms of what they do, how they look, and how they smell; being a burden to their families—not only a physical strain, but also a financial hardship; and dying alone in pain.⁵ Any one of these concerns causes a patient to suffer and therefore must be addressed to provide good management of pain symptoms.

Physical pain is not universal with every death, but discomfort is usually present. All physicians should be concerned with relief of symptoms, and they should focus on end-of-life care as part of comprehensive patient care. Pain therapy may become an issue for care at anytime in the dying process. Physicians must be able to address adequately the role of pain with end-of-life patient care. Knowledge of the principles of providing proper pain management at the end of life can enhance the physician-patient relationship.

Total Pain—Physical Pain

Physical pain is the most familiar component of the total pain concept for physicians. Assessment includes eliciting a history of presenting symptoms as well as conducting the appropriate physical examination. Laboratory and imaging studies may be used to further understand the patient’s pain.

Physical pain can be categorized in terms of its temporal nature (ie, acute or

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chronic) and delineated as to three types based on neurophysiologic mechanisms (ie, somatic, visceral, and neuropathic) (Figure 3). Regardless of mechanism, breakthrough and incident pain may occur.

Acute Pain

Acute pain results from nociceptor stimulation, usually is time-limited, and often responds to analgesic medications or osteopathic manipulative treatment. Pain perception is usually the result of an acute injury such as a surgical intervention and can occur at end of life.^{3(p17),4 (p299)}

Chronic Pain

Determination of chronic pain is based on duration of pain beyond three months after an acute injury. Acute pain can be resolved, but chronic pain must be managed and presents an entirely different challenge to both patient and physician. Two goals of treating patients with such pain are reduction of related symptoms and restoration of maximal function. Chronic pain is often multifactorial, sources being as diverse and additive as that from migraine headache, osteoarthritis, dental caries, diabetic neuropathy, and cancer, all of which may occur in the same patient. Delineating and targeting treatment for each symptom allows for optimal symptom relief and better global functioning.^{4(p299)}

Somatic Pain

Somatic pain results from stimulation of nociceptors in the skin and deep musculoskeletal tissues. It is described as being a well-localized “deep aching feeling” with tenderness to palpation. Common sources of somatic pain are arthritic joints, osteopathic lesions, fractures, and abscesses.^{3(p23)}

Visceral Pain

Visceral pain occurs from stretching or activation of nociceptors in the linings or serosa of organs. In contrast to somatic pain, visceral pain is difficult to localize and is described as “deep pressure,” “cramping,” “spasms,” or “squeezing.” Nausea, diaphoresis, and emesis are frequently present. Palpation over the site may elicit an accompanying somatic pain.^{3(pp24,52)}

Neuropathic Pain

Neuropathic pain results from damage to the peripheral nervous system or the central nervous system (CNS), or both. It is described as “sharp,” “electric,” or “burning,” singly or in combination, and is usually found in the same distribution pattern as a sensory peripheral nerve. Pain resulting from trauma to the CNS that partially or completely separates the CNS from the peripheral nervous system is termed *deafferentation pain*.

Central pain may be the result of a cerebral vascular accident and is characterized as “vicelike” or “throbbing,” or both; headaches are described as “dull” and “never relenting.”^{3(pp21,24)}

Breakthrough Pain and Incident Pain

Breakthrough pain is characterized as a temporary increase in pain from the basal, acute, or chronic pain level. It is frequently described as worsening pain at the latter part of the regularly scheduled analgesic-dose interval. Incident pain can occur during diagnostic or therapeutic procedures, or it may be caused by physiologic maneuvers such as valsalva when passing flatus. Physicians should anticipate each of these types of pain and have the appropriate comprehensive pain management in place.^{3(p34)}

Pain Scales

The several types of pain scales are universally used for patients to convey the intensity of their pain throughout treatment. Physicians should ask patients to describe the nature of the pain as well as the severity. Patients and healthcare professionals concur in their perceptions when pain is of moderate intensity. Pain of moderate to severe intensity is often accurately reported by patients and undervalued by healthcare professionals. Using a particular pain scale is not as important in the care of patients as the consistent use of the same pain scale. The endpoint of therapy should be the patient’s perception of an acceptable pain level⁶; and physicians should always believe their patients.^{3(p17)}

Total Pain—Anxiety

The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition Text Revi-

sion (DSM IV-TR) defines anxiety as the apprehensive anticipation of future danger or misfortune accompanied by a feeling of dysphoria or somatic symptoms of tension.^{7(p820)} The focus of anticipated danger may be internal or external.

Anxiety may be due to many organic causes (Figure 4) and may occur in the course of pain management if patients are not receiving the prescribed pain medication(s), or are given an inadequate amount or reduced frequency. Anxiety may also be caused by altered metabolic states such as coronary occlusion, hypocalcemia, hypoglycemia, hypoxia, delirium, occult bleeding, tumors (especially pheochromocytoma, thyroid, parathyroid, insulin- or ACTH-producing tumors), and sepsis. Relief of organic-based symptoms caused by these conditions often ameliorates a patient’s anxiety. Acute alcohol withdrawal, rapid tapering of corticosteroids, and side effects of bronchodilators can cause symptoms of anxiety. Metoclopramide use is frequently associated with negative emergent akathisia resulting in a patient’s feeling anxious. Anxiety may also be preexisting and should be managed as any other comorbid medical condition.^{8(pp304,305),9(pp748-750)}

Even when patients are adequately treated, the thought that pain relief will not be available at the end of life causes some to have great anxiety. Abandonment by their physicians, families, or friends, as well as fear of dying alone, is another source of symptomatic anxiety at the end of life; this is the reason to conduct research to evaluate novel treatment modalities. The US Food and Drug Administration is currently permitting a Phase II dose-response pilot study of +3,4-methylenedioxymethamphetamine (street drug Ecstasy) to evaluate its effectiveness in reducing anxiety and bringing about a sense of calm in patients with advanced cancer (<http://www.maps.org/research/mdma/canceranxiety/proto colfda.pdf>).

Total Pain—Interpersonal Interactions

Interpersonal conflict influences development of pain as much as any other aspect of this clinical situation (Figure 4). Families and individuals who coped well

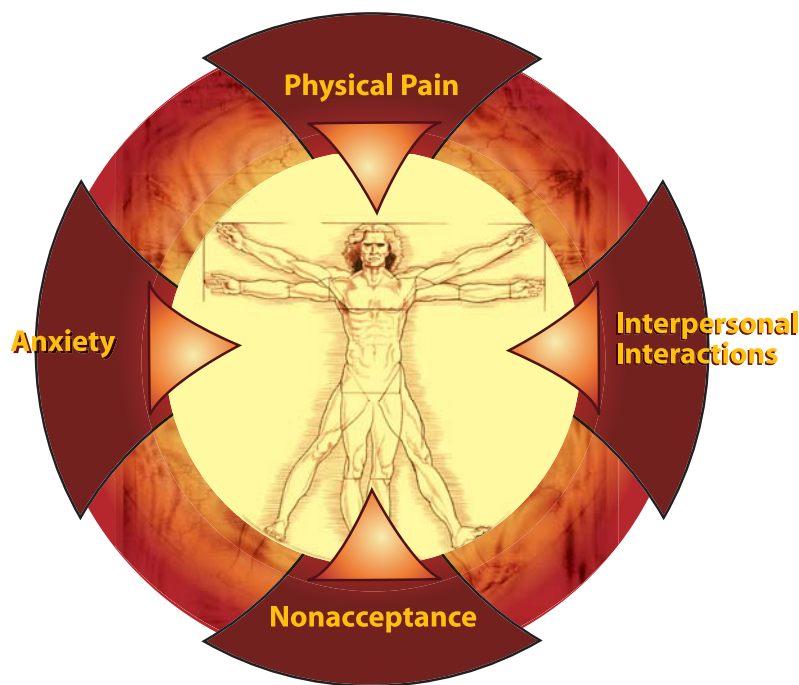
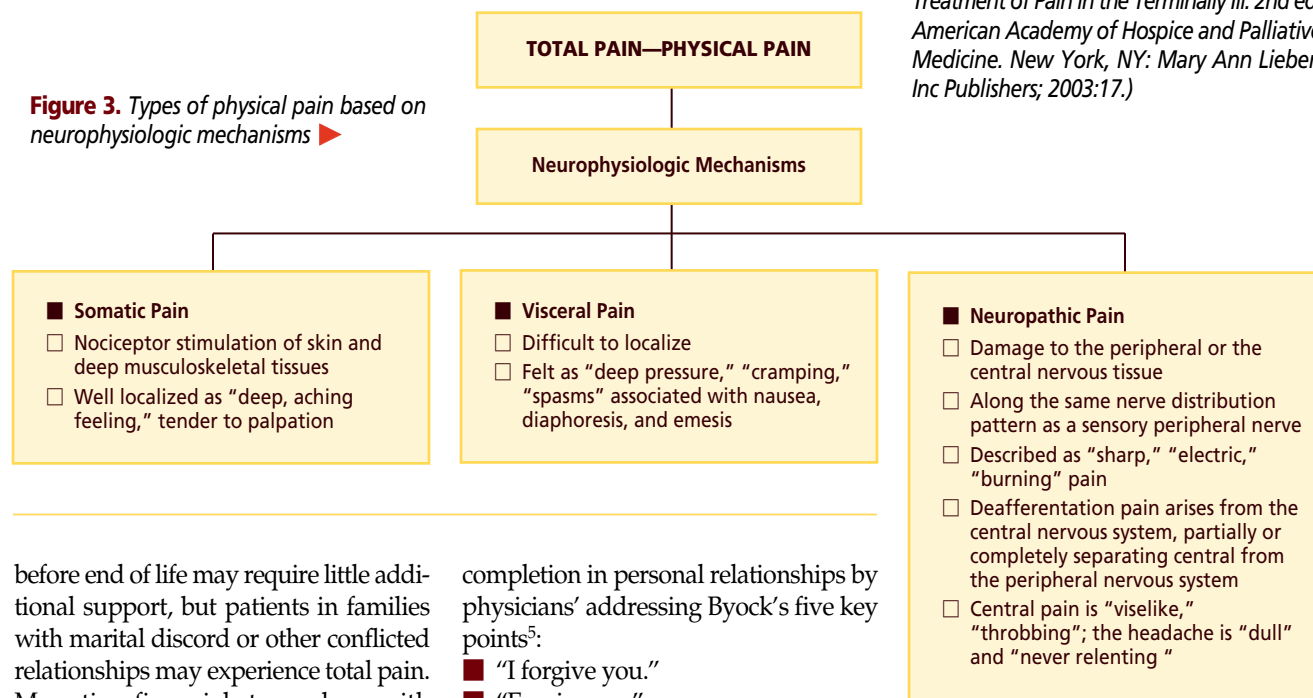


Figure 1. Four components of “total pain” concept depicted with Da Vinci’s Vitruvian Man representing person.

- P** — Physical pain:
Osteopathic lesion, deep tissue
or bone pain “tender”
- A** — Anxiety: rage, depression
- I** — Interpersonal interactions:
family strains, isolation
- N** — Nonacceptance of the caregivers:
doubting of their faith,
sense of hopelessness

▲ Figure 2. Patient’s perception of “total pain.” (Adapted with permission from Storey P, Knight CF. *UNIPAC Three: Assessment and Treatment of Pain in the Terminally Ill*. 2nd ed. American Academy of Hospice and Palliative Medicine. New York, NY: Mary Ann Lieber, Inc Publishers; 2003:17.)

Figure 3. Types of physical pain based on neurophysiologic mechanisms ▶



before end of life may require little additional support, but patients in families with marital discord or other conflicted relationships may experience total pain. Mounting financial stress along with family discord may cause additional disharmony. A loss of status within the workplace or family can intensify pain symptoms. Whereas analgesic medication and anxiolytics cannot quell the pain of interpersonal conflict, counseling often can be of assistance. Patients at end of life can achieve comfort and a sense of

completion in personal relationships by physicians’ addressing Byock’s five key points⁵:

- “I forgive you.”
- “Forgive me.”
- “Thank you.”
- “I love you.”
- “Goodbye.”

Total Pain—Nonacceptance

Acceptance at life’s end is a self-acknowledgment of the imminence of death. Buckman’s *Three-Stage Model of the Process*

of Dying offers a guide for physicians to anticipate how patients accept their finality in terms of personal spirituality^{9(pp144-146)} (Figure 4). In the initial stage, the patient has awareness of the definitive reality that the disease process will

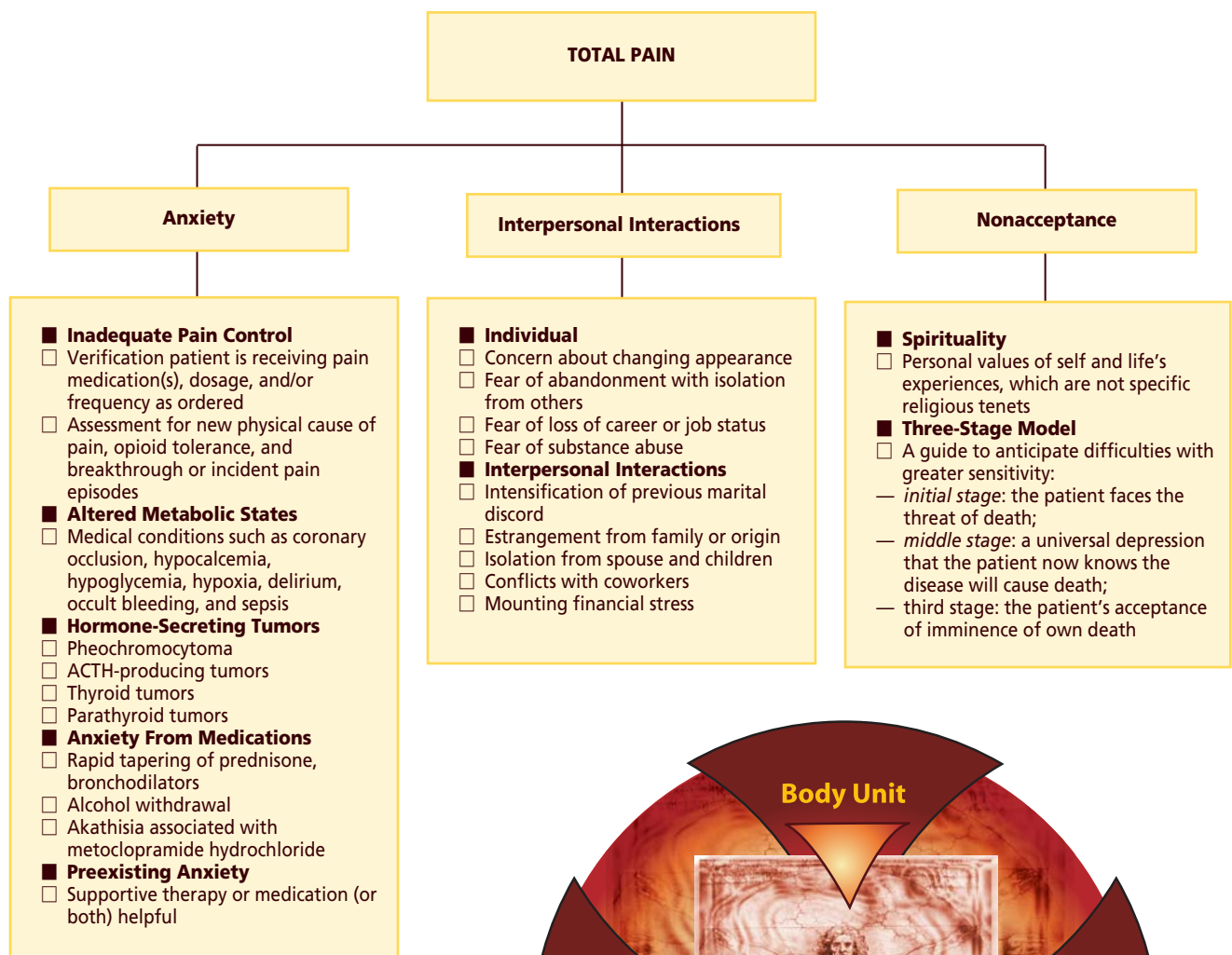
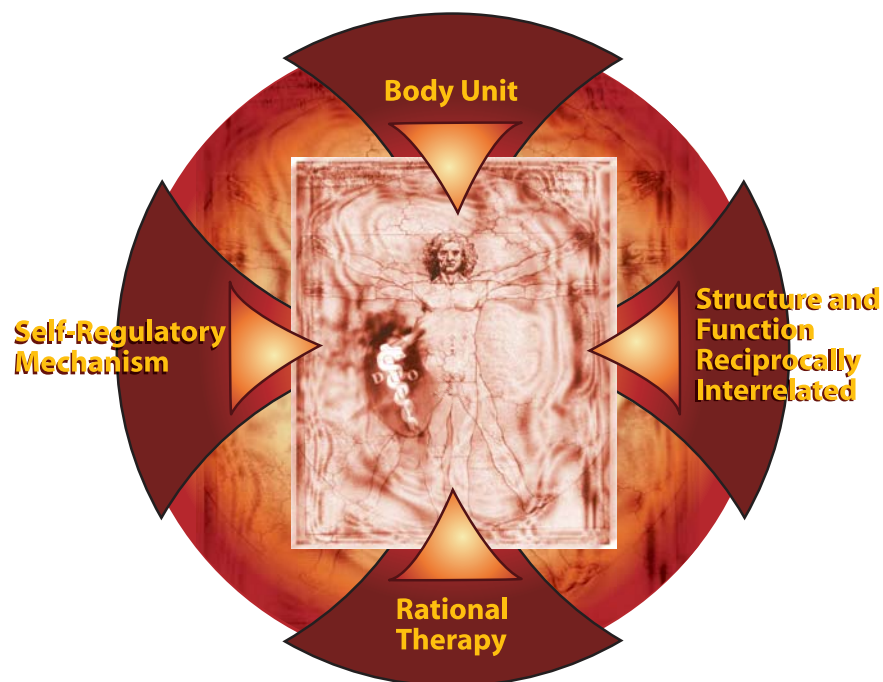


Figure 4. Aspects of "total pain" concept depicted with Da Vinci's Vitruvian Man representing person

Figure 5. Components of osteopathic philosophy related to concept of "total pain" depicted with Da Vinci's Vitruvian Man representing person. ▶



possibly result in death. Reactions to such awareness are characteristic of an individual's basic personality, and may include fear, shock, anger, guilt, and vacillation between hope and despair.

In the middle stage, most patients resolve their anger and denial. Depression is common here as individuals are aware they will indeed die, but they do not view death as immediate. Supportive family and friends are helpful, but if the dying person has negative interpersonal conflicts, professional counseling should

be offered. Others in this intermediate phase have an intensified positive emotional resolve.

The third stage is defined by acceptance of the imminence of their death. Nonacceptance is evidenced by intense distress with the proximity of death, and is a source of increased total pain. This model is helpful for physicians who may

anticipate the need for support of patients at the end of life.

Spirituality is a function of personal values, not specific religious tenets. Hay¹⁰ provides a spiritual model that is compatible with medical constructs for good end-of-life care. There are four versions of individual spirituality according to Hay:

■ Spiritual suffering is the presence of interpersonal or intrapsychic pain.

■ *Inner resource deficiency* is defined as having diminished spiritual capacity.

■ *Belief system problem* is a lack of conscious awareness within a personal meaning system.

■ *Specific religious requests* that are made by some individuals at the end of life assist them in obtaining a sense of spiritual well-being.¹⁰

Pain Management in End-of-Life Care

Effective pain management at the end of life applies the concept of total pain. Before physicians prescribe analgesics, an assessment is required to determine the nature of the pain. Physicians must treat patients for reversible physical causes and address interpersonal and spiritual pain. Analgesics will be most effective if physicians explore all components of total pain.

Opioids are often the medication of choice for end-of-life pain. They are safe and effective for treating patients with moderate to severe pain, and they have side effects that can be managed effectively.^{3(p17)}

Myths continue to limit the use of opioids. Physicians often avoid using opioids fearing the addiction of their patients. *Addiction* is known psychiatrically as substance abuse, a condition defined by the *DSM IV-TR* as a maladaptive pattern of substance use manifested by recurrent and significant adverse consequences related to the repeated use of the substance.^{7(p198)} The pre-opioid state of a patient—not merely exposure to opioids—determines the potential for opioid abuse. Active substance abusers requiring end-of-life pain management challenge the most tolerant of medical care systems. Analgesic therapy must be given until death. Physical dependence must also be medically managed during dying.^{8(pp372-373)}

Patients and their families may delay the use of opioids fearing their use foretells imminent death, and patients may fear that opioid use early in their care will diminish the effectiveness of such medication. It is the responsibility of physicians to counsel patients that this result will not be allowed to occur. Dose



Figure 6. Suggested references.

adjustment, appropriate monitoring, and management of adverse reactions must continue for all patients.^{3(pp25-33)}

Nausea, sedation, and pruritus are common temporary side effects of opioids^{10(pp81-86)} and usually resolve within 3 to 5 days of continuous administration.¹ Antihistamines such as diphenhydramine and hydroxyzine are effective for treating patients for nausea and pruritus.^{11(pp81-86)} The elderly may experience confusion, hallucinations, and cognitive impairment with opioid use. A different opioid at a lower dose may help; however, advancing disease may be the cause

of confusion in geriatric patients.^{3(p32)}

Constipation, the most frequent side effect that occurs with sustained opioid therapy, should be anticipated and prevented; this adverse effect can cause bowel obstruction. Liberal use of laxatives, hydration, and exercise facilitate bowel function with ongoing opioid therapy.^{3(pp35-39)} Herrmann¹² suggests that osteopathic manipulative treatment has a definite role in the prevention and treatment of postoperative adynamic ileus. Intermittent pressure applied to the lower thoracic and lumbar spine with the patient in the supine position for

approximately 2 minutes every 2 hours is effective.

Opioid overdose is rare; signs include myoclonus and respiratory depression. Physicians should consider opioid toxicity when patients' level of consciousness declines, and respirations are fewer than 6 per minute. These conditions may also represent disease progression or active dying. Other physical signs of opioid toxicity are myoclonic twitching, constricted pupils, and skeletal muscle flaccidity with cold or clammy skin.^{3(pp25-27,40)}

Pain Management in Children at End-of-Life

In 2004, 56,261 American children died. Half (27,936) of these deaths occurred in the first year of life. In regard to infants, 50% died as neonates in the first month of life. Leading causes of death in childhood include disorders of prematurity, congenital anomalies, neurologic disorders, and cancers.¹³

Pain is a significant component of all these conditions. According to the World Health Organization (WHO) disseminating and implementing current principles of palliative care, including pain relief and symptom control, would have the most significant impact on the quality of children's lives. In the developed world, according to the WHO, major sources of pain in pediatric cancer are diagnostic and therapeutic procedures, whereas in developing countries, most pain is disease-related. A unique aspect of pediatric pain at the end of life is that children, unlike adults, cannot independently seek pain relief and are therefore vulnerable; the presence of adults is required to be able to recognize such pain and to implement such therapy.¹⁴

Good pain care in children should be tailored to their unique metabolism and pathophysiology as well as their life-limiting condition. It is best delivered by the oral route, in a palatable form, and scheduled around the-clock. Attention to reassessment of the child's pain level includes evaluating the need for and type of breakthrough doses and appropriately preparing for any negative emergent effects of such medication.

Medications such as codeine

(methylnormorphine), hydrocodone, hydromorphone, morphine, etc that target the mu receptor are appropriate for treating moderate and severe pain in children. Opioids, specifically morphine sulfate, have a delayed clearance in the first 3 months of life. Initial doses in infants should be one third to one half of those recommended for older children. Reassessment and iteration is the gold standard for pediatric pain control. Infants may be more sensitive to respiratory-depressant opioids than children older than 1 year, but increased somnolence always precedes this serious toxicity at any age. Children, as well as adults, frequently become somnolent upon obtaining relief of their moderate to severe pain symptoms. Opioids have no upper dosage limits, and the rate of opioid elimination at the first year of life exceeds that of the adult.¹⁵

Total Pain—Osteopathic Medical Care

Osteopathic medical care is based on osteopathic philosophy (Figure 5); the four components being:

- The body is a unit.
- The body has self-regulatory mechanisms.
- Structure and functions are reciprocally interrelated.
- Rational therapy is based on these principles.

Harmony among these components results in good health,¹⁶ but patients at end of life are not in a state of harmony and hence in poor health. The body cannot support infinite life; therefore, self-regulatory mechanisms are unable to rectify the end-of-life process, and functioning at this stage is disruptive, causing changes in mechanical structure. Rational therapy would be to return the body to a unit in which structure and function are reciprocally interrelated.

End-of-life care is the rational therapy that allows for reduction of pain symptoms and facilitation of as much function as possible. Application of the four components of osteopathic philosophy is consistent with management of total pain as death approaches.

Administration of osteopathic manipulative medicine can relieve some acute and chronic physical pain. Osteopathic techniques used in postoperative patients have application at the end of life. Gentle direct or indirectly administered myofascial release techniques have been used for treatment of patients with chronic pain. High velocity techniques are usually not used.¹⁶⁻¹⁹ The physician's touch demonstrates patient acceptance and relieves fear of isolation and abandonment.^{4(pp301)} Osteopathic physicians should incorporate osteopathic principles into their management of total pain in patients at the end of life.

Comment

Good pain management at the end of life need not be daunting for patients and physicians. Regardless of their type of specialty practice, physicians encounter patients at end of life. Knowledge of total pain concepts incorporated into end-of-life pain management offers much to patients and their physicians. Osteopathic principles and osteopathic manipulative treatment should be integrated into quality pain management for all patients at the end of life.

Figure 6 provides some helpful resources for end-of-life care.

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"Out of the Mouth of Babies..."*

Vignettes are helpful in framing a clinical picture. Pain is a profound problem, no matter the age of the person. The following vignette with words written by a bright adolescent before his death exemplifies pain experienced within a family. Gratefully, Scotty's mother Mrs. Kathleen Russell approved publication of the following vignette.

Scotty was born August 4, 1987, weighing 6 pounds, 4 ounces. He died pain free on January 18, 2004, weighing 31 pounds at age 17 years from inanition secondary to a mitochondrial disorder with resulting short-gut syndrome. The most Scotty ever weighed was 34 pounds. He had undergone right nephrectomy, colostomy, and total gastric resection. He had several bouts of pancreatitis. At the age of 11, he suffered neuronal hearing loss due to antibiotic toxicity. Scotty was nutritionally sustained by Broviac parenteral nutrition. This sustenance was complicated by several infections accompanied by profound and unrelenting pain.

A photograph of Scotty as a toddler shows a large callous on his forehead from pounding his head to the floor in pain. He constantly had a sad expression. Attempts to administer a pain block were unsuccessful. His surgeon requested a pain consultation.

After the consultation, morphine sulfate was prescribed for around-the-clock oral administration to Scotty. The morphine dose was titrated to allow maximum pain relief, which allowed Scotty to return to regular school work, enjoy the Red Wing hockey games, and most of all, to be an active part of his family.

Scotty sent the following e-mail message from California about his maternal grandfather. His words capture the essence of pain control: to allow the best functioning of a person while being pain free.

"Dr. L

My Grandpa has cancer and is very sick. His doctor told us he wasn't going to make it. This makes me very sad. He is always so good to me. He used to live by us and we'd see him all the time. Last year he moved to San Diego because he was always cold. He didn't like winter and snow. Now I don't get to be with him much. We just went out to see him because he has been very sick. I went to the doctor's with him while I was there....

"My Grandpa was in a lot of pain and hurt all the time. He needed something to help him. His doctor said he could take Darvocet every six hours. This was not helping him because he would hurt much sooner than six hours. He needed something more often and stronger. His doctor said no because he would get addicted. This made me so mad because his doctor was being stupid! My Grandpa is going to die in a couple months and his doctor is worrying about him becoming addicted instead of helping him feel better for the time he has left. We don't want him to be sad all the time because he is hurting. I'm only a kid, but in my heart I know it would be better to help him. It makes no sense to me to let a person hurt when I know doctors can help them....

"I used to have major pain and cry all the time. I couldn't do anything. I was always sad. I couldn't concentrate to do anything. I didn't sleep good. I hurt all the time. A lot of doctors wouldn't give me anything to help my pain either. My doctor finally listened and helped me. I take morphine every day. I am not addicted. I am doing 'great' in school for the first time. I am doing work that's right for my grade. I even like it now. I can focus. I am learning alot. I even sleep longer at night. I still have pain, but I can tolerate it better this way. I do not think this is a bad thing. I know it is right! I want my Grandpa to be helped, too. I know his doctor was so wrong in telling him this. It makes no sense at all. I hope and pray that his doctors help him feel better so he can be happier with the time he has left. NO ONE SHOULD HAVE TO LIVE IN PAIN!!! Medicine can work."

—by Scotty Russell, age 12.

Mrs Russell wished to add, "We all die. Scotty and I don't want anyone to watch as much suffering and pain as we did until we received knowledge and help."

*Psalm 8:1-2 (KJV).