Most people assume that dying involves pain. In fact, a substantial number of people (perhaps 15-20 percent) experience no pain or discomfort at the end of life. Most of the rest (70 percent) have modest discomfort that is easily managed. For example, every patient admitted to Providence Hospice of Seattle automatically gets a medication pack called the “comfort kit,” with contents that include morphine, lorazepam, and bowel meds. Quite a few patients never have the need to even open their comfort kit.

Rarely, a patient experiences pain that is refractory to aggressive management. This may arise only once or twice a year among the many hundreds of patients managed every year. To help these patients, we may initiate an intervention called palliative sedation.1 For the patient, this involves continuing what are usually large doses of IV opiates and benzodiazepines, and adding phenobarbital at anticonvulsant doses. The following case illustrates the therapeutic use of palliative sedation:

“John” was a 51-year-old man with lung cancer which had metastasized widely and produced pathologic fractures of his pelvis and spinal cord compression at T10. His bone pain was originally managed with IV morphine, steroids, and occasional lorazepam doses, as well as several other adjuvants as needed (acetaminophen, vistaril, fentanyl). When his pain escalated, morphine was increased to doses of several hundred milligrams per hour without any apparent relief. John then exhibited the unfortunate side effect of myoclonus.

The opiate was rotated to hydromorphone, without significant improvement. At this point, John was receiving 300 mg of hydromorphone per hour with liberal boluses and lorazepam 5 mg every half hour. He was still arousable and clearly remained in serious discomfort. Palliative sedation was indicated as the next step toward pain relief for John.

Phenobarbital can be added in loading doses of 200 mg IV given every four hours, up to five doses the first day, followed by one to three doses on subsequent days. John became completely comfortable after four doses of phenobarbital on the first day. He was in deep sleep, although still somewhat arousable. Both John and his family were constantly attended to by the hospice team. During palliative sedation, there was frequent communication between the hospice team, the primary care physician and the hospice medical director.

John received two doses of phenobarbital per day on day two and day three. His brother arrived from out of state the following day and phenobarbital doses were held. He became more arousable and able to interact with his brother. Pain re-emerged, and after the visit, another phenobarbital dose was given, returning him to a comfortable state. John received two doses per day for the next four days and died comfortably at home, with loved ones present.

When we employ palliative sedation, we seek complete consensus among all the patient’s loved ones and within our administrative team, and together we assure that this intervention is indeed warranted. We formally invoke the principle of double effect — the ethical principle that pain relief is our one and only goal, realizing that an additional secondary effect may be shortening length of life. In actuality, this principle is invoked any time we use almost any medicine, as most medicines have severe side effects in some instances. In any case, there is substantial evidence that palliative sedation does not shorten life, but rather that it may lengthen survival. It certainly improves the quality of life when its administration is warranted.2 Palliative sedation is a powerful tool in our arsenal of pain management options. Fortunately, it is only needed on rare occasions. It gives our hospice care team significant empowerment, knowing that they have this very dependable intervention available.

See “Palliative sedation” on page 2
Medications used in palliative sedation

By Kristen Eglington

The decision to implement palliative sedation is made when all other options to treat a patient’s symptoms have been exhausted. The most refractory symptom is often pain; however, any refractory symptom (such as agitation or dyspnea) that causes suffering in the dying patient may be addressed with palliative sedation. This article will briefly outline the most common medications used.

Typically, patients will already be on routine opioids. These should be continued to prevent any withdrawal symptoms and to treat pain, however, opioids should not be used for the purpose of sedation. Opioids do not provide a sustained level of sedation and myoclonus and seizure may result from use of high doses of morphine, hydromorphone and fentanyl, limiting further titration.

Midazolam is the most commonly used benzodiazepine for palliative sedation. It provides very rapid induction with a short half life (two to six hours) and can be given via a continuous IV or SQ infusion.¹ It has a stability of at least 10 days when protected from light.² This allows for its use in settings where on-site pharmacy is not available. A bolus dose of 5 mg is usually given, followed by a continuous infusion starting at 1 mg/hr with subsequent rapid titration until desired sedation is achieved.¹ This short half life also allows for a fast reversal of sedation, if desired, so that a patient can interact with family.

Lorazepam is another benzodiazepine, which can also be given via IV or SQ continuous infusion. Dosing is similar to midazolam, however, propylene glycol accumulation and subsequent metabolic acidosis is seen in doses greater than 10 mg/hr.¹ Its stability is three to five days and potentially requires more pharmacy support.² The longer half life (12 hours) does not allow for as rapid titration or reversal compared to midazolam.

As shown in Dr. McCormick’s case study (see front page), a patient may already have been receiving high doses of benzodiazepines prior to the decision to initiate palliative sedation. When despite high doses of benzodiazepines, symptoms persist, the next step is usually to begin barbiturates.

Phenobarbital, a barbiturate, can be given IV or SQ. Its long half life (one and a half to five days) allows for intermittent, versus continuous, dosing.¹ There are varying approaches to using phenobarbital for sedation. A retrospective analysis of the use of phenobarbital in the management of agitation and seizures at end of life found patients on average receive 1200 mg/day via continuous infusion. Other patients receive intermittent injections of 100-200 mg.⁴ At Providence Hospice of Seattle, a 20 mg/kg loading dose is given on day one in 200 mg increments, then 100-200 mg daily and every four hours as needed for symptom management on subsequent days.

All three medications discussed may also alleviate the myoclonus and seizures associated with opioids, working in concert with pain management and sedation. Further medical monitoring in addition to level of sedation and relief of distress is generally inappropriate in the dying patient. Prior to initiation of palliative sedation, the goals of care are discussed and agreed upon by all family members and the hospice care team, so that patient comfort is understood to be the intervention’s primary goal.

1) Micromedex www.thomsonhc.com/hcs/librarian Accessed 09/02/09
2) King Guide to Parenteral Admixtures. www.kingguide.com Accessed 09/02/09

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Palliative sedation from front page

to help in these difficult-to-manage cases. Knowing this is available, they can communicate to families and patients with confidence, assuring them that they will do everything in their power to relieve discomfort, and that they will stop at nothing to manage pain optimally.


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Sustaining hope, delivering prognosis: An approach to exploring patient needs

Asking ‘How much information do you want?’ is not enough

Addressing patients’ simultaneous needs for physicians to both support their hope and to deliver explicit prognostic information about their life-threatening illness is challenging. Lack of physician understanding of patient needs in this type of communication can pose a serious barrier to end-of-life care discussions.

That is according to researchers at the University of Washington, Seattle, who have developed an approach that may help physicians understand how individual patients and their families incorporate the dual needs for hope and information, and thus how best to tailor delivery of prognostic information.

“[P]atients and families differ in their needs and desires for hope and explicit prognostic information,” write the authors of a report in the Journal of Palliative Medicine. “[W]e found that simply asking patients how much information they want, without exploring their emotions and concerns, did not adequately elicit informational needs.”

The investigators analyzed responses gathered in multiple in-depth interviews with 147 participants in the Seattle-Tacoma area: physicians practicing in pulmonology, oncology, or internal medicine (n = 31); their patients with either advanced cancer or severe chronic obstructive pulmonary disease (COPD), about whom the physicians “would not be surprised if the patient died from any cause in the next year” (n = 55); family members (n = 36); and nurses identified by patients or physicians as involved in discussions of patient illness (n = 25).

Initially, when asked how much information they wanted about the patient’s illness, all patients and family members declared that they would want “all” the information; but upon deeper questioning, a substantial minority expressed reservations about knowing certain types of explicit information.

For the deeper exploration, patients and family members were invited to discuss each diagram in a four-diagram conceptual model depicting different methods of integrating hope and the need for information (e.g., alternating between hope and information; balancing both; integrating hope and information; redirecting hope).

Key findings

◆ Patients and families varied greatly in their desires for hope and explicit prognostic information.
◆ Simply asking, “How much information do you want?” was an unrevealing approach to understanding individual needs.
◆ The four-diagram approach enabled patients and families to explain their concerns and preferences for delivery of prognostic information.

◆ Based on the diagram chosen, respondents described their preferred prognosis communication approach, which resolved into one of two methods: direct and indirect.

Indirect approach

The indirect approach to conveying prognostic information, as recommended by participating patients and families, included such physician strategies as:

◆ Taking into account the fragility of the patient’s and family’s emotional states
◆ Avoiding blunt or precipitous statements
◆ Verbalizing a commitment to non-abandonment
◆ Suggesting a clear and comprehensive care plan
◆ Presenting outcomes for groups rather than for the individual patient

Direct approach

For the direct approach, respondents invited physicians to communicate fully and explicitly what could happen in the future. “These participants were able to manage the emotional impact of prognostic information, and were less dependent on the clinician to facilitate their emotional adjustment to the news,” the authors comment.

“[P]hysicians’ inability to balance concerns about providing prognostic information with supporting patients’ hope may be an important barrier to communication with patients and families about end-of-life care,” the authors write.

They note that their four-diagram model may be a useful clinical tool for understanding individual patient and family needs and thus improving physician-patient/family communication, but recommend further research.

Source: “An Approach to Understanding the Interaction of Hope and Desire for Explicit Prognostic Information among Individuals with Severe Chronic Obstructive Pulmonary Disease or Advanced Cancer,” Journal of Palliative Medicine; May 2008; 11(4):610-620. Curtis JR, Engelberg R, Young JP, Vig LK, Reinke LF, Wenrich MD, McGrath B, McCown E, Back AL; Department of Pulmonary and Critical Care Medicine, Department of Gerontology and Geriatric Medicine, Department of Biobehavioral Nursing and Health Systems, Department of Medicine, Department of Oncology, University of Washington, Seattle.

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Physician spiritual assessment tool available online at gwish.org

The George Washington University Institute for Spirituality and Health (GWish) maintains an online resource for promotion of a “more compassionate and integrated” system of health care through the recognition of the spiritual dimension of health and suffering.x

The website (www.gwish.org) offers general recommendations for physicians taking a spiritual history, as well as internet links to relevant outside websites, pertinent publications, and references. FICA, the acronym for a physician spiritual assessment tool developed by GWish founder and director Christina M. Puchalski, MD, of the university’s school of medicine, is available online or can be ordered in pocket card format.

FICA Spiritual Assessment Tool

F Faith, belief, meaning: “Do you consider yourself spiritual or religious? Do you have spiritual beliefs that help you cope with stress? If not, what gives your life meaning?”

I Importance and Influence: “What importance does your faith or belief have in your life? Have your beliefs influenced you in how you handle stress? Do you have specific beliefs that might influence your health care decisions?”

C Community: “Are you part of a spiritual or religious community? Is this of support to you, and how? Is there a group of people you really love or who are important to you?”

A Address/Action in care: “How would you like me, your health care provider, to address these issues in your health care?”

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