



## Pain Management and Assessment at the End of Life

By Michael Robinson, MD

There have been many articles and books written about pain management and assessment addressing chronic non-malignant pain, cancer pain, implanted devices to aid in pain management and others dealing with pain at the end of life. Most articles have dealt with assessment tools, primarily in patients who are cognitively unimpaired or who can speak English. This article will primarily focus on the following issues: pain assessment in those who are culturally diverse or cognitively impaired; and the ethics of end-of-life pain management.

It is estimated that the population of the United States is now one-third non-White. The Sioux Falls School District estimates that 19 percent of its enrolled students are non-White, illustrating cultural diversity even here in South Dakota. There is no doubt that other communities in South Dakota have or will have an equally diverse culture. To communicate with this culturally diverse population, we must have a plan in place to deal with pain assessment issues, especially at end of life. We know that those

approaching the end of life with cancer or other chronic illnesses fear pain as a result of their illness.

Before we can adequately deal with diverse cultures, we need to reflect on our own attitudes, beliefs and prejudices. Mistrust in physicians may be an issue particularly in certain ethnic cultures. Physician perception of patients may be influenced by ethnicity. As a result of misperceptions, minority patients are less likely to receive adequate analgesics for cancer pain relief and less apt to have completed advance directives.<sup>1</sup> In one survey, physicians had a negative stereotype about black patients that included a perceived higher risk of noncompliance and substance abuse.

We also need to understand the particular cultural practices and beliefs regarding pain management and assessment. In some cultures, asking about pain may be disrespectful because admitting pain may be related to admitting weakness. Instead, we should ask about the patient's comfort. In certain cultures, referring to a patient by his or her first

name might also be disrespectful.

Symptom management in other cultures requires attention to differences in the meaning and expression of pain and suffering in addition to perceptions and customs related to touching or handling the human body. In certain cultures the concept of patient autonomy and informed consent is alien; often family members are the decision-makers instead of the patient. We want to specifically determine how decisions are to be made about the patient's medical care and ask whether the patient holds a belief that is prevalent within a culture. It may be worthwhile investigating folk remedies or cultural practices in dealing with or evaluating patients with pain.<sup>2</sup>

The American Academy of Family Physicians (AAFP) has published cultural proficiency guidelines on end-of-life care. Principle 5 states "Care at the end of life should recognize, assess and address the psychological, social, spiritual/religious issues and cultural taboos realizing that different cultures may require significantly different approaches."<sup>2</sup>

Pain assessment and communication may be difficult in this diverse population. Quite often there is a language barrier which may require the use of a translator, and published guidelines for the use of translators are as follows: the translator should not be a family member (family members may misinterpret, filter, summarize or censor sensitive subjects); a pre-visit discussion with the translator should outline what will be covered in the encounter; and there should be a literal word-for-word translation of any unfamiliar terms.

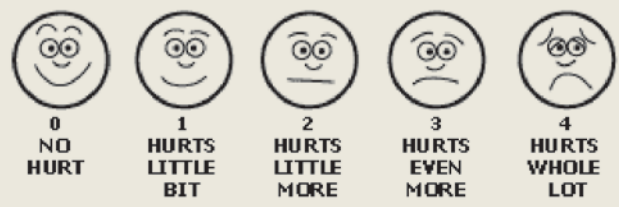
Prior to the encounter the spokesperson for the patient and family should be identified, since some cultures prefer information be given only to the caregiver or decision-maker, not the patient. During the interview the patient should be looked at while being addressed in the second person, written instructions given and confidentiality respected. Disclosing information to the wrong person (sometimes the patient) may be seen as disrespectful or impolite, provoke anxiety or depression, eliminate hope, and in some cultures the word may "come true" if spoken.<sup>2</sup>

Various sources including "Last Acts" indicate pain is frequently a problem in the nursing home population. Studies demonstrate that we don't adequately manage or assess pain in nursing homes.<sup>3</sup> Studies report as many as 40 to 80 percent of nursing home residents are in some type of pain, and South Dakota nursing homes are no different. In these patients with pain, only 50 percent have adequate relief of their symptoms. This reflects a problem in the recognition as well as treatment of pain in the nursing home setting.

What about pain assessment in those cognitively impaired?

Here we are not dealing with another culture but an inability to effectively communicate. Patients with severe cognitive impairments tend to have fewer complaints and are less able to report pain. Therefore, to determine the presence of pain we often have to rely on pain behaviors such as facial grimacing, verbal reports or vocalizations, body movements, interpersonal interactions, mental status changes, or changes in appetite. In those who can somewhat communicate a typical number scale, a facial scale or a color scale can be used to determine the presence of pain (Figure 1).<sup>4</sup>

Figure 1.  
Typical number and facial scale for determining



In those less able to communicate we need to rely on family or caregivers to report changes in behavior that may indicate pain. This observation of pain behaviors includes changes at rest and with activity, assuming that if it would cause us pain it is likely causing the patient pain. In these patients, changing behavior(s) may be due to pain or non-pain causes such as infection, constipation or a primary mood disorder. In some instances, if behavior is changing and pain is a possibility, consider an analgesic trial such as scheduled acetaminophen, if not contraindicated. Regular assessment and monitoring of response to interventions are paramount. Remember that physiologic parameters may be unreliable indicators of pain.

There are several tools for evaluating pain in the cognitively impaired: the Doloplus-2 scale which scores somatic, psychomotor and psychosocial reactions. Scores greater than five out of 30 suggest pain as a reason for various reactions.<sup>5</sup> Other scales used in the geriatric population includes the Non-communicative Patient's Pain Assessment Instrument (NOPPAIN) which assesses everyday activities (sitting, standing, walking, and transferring in and out of bed) and reports of pain by the patient or an observer.<sup>6</sup> Other pain assessment tools include the PAINAD scale (Pain Assessment in Advanced Dementia).<sup>7</sup>

In 2005 new guidelines were published by the American Pain Society (APS) regarding treatment of cancer pain in children and adults. These guidelines include less emphasis on the "ladder approach," regular screening and assessment, use of a pain diary and newer titration algorithms for pain, particularly for a pain emergency. Someone presenting with

a pain emergency (pain rated seven to 10 on a 10-point scale) should initially receive strong opioids (i.e., morphine, oxycodone, fentanyl) for primary treatment and not weak opioids or non-steroidal analgesics. There are published pain algorithms by the APS and the National Comprehensive Cancer Network (NCCN) regarding medication titration in a pain emergency that involve rapid titrations based on the peak effect of the analgesic and ongoing assessment. There are also published guidelines for patients who present with pain that is rated 4 to 6 or less.<sup>8,9</sup>

What about the ethics of pain management? Does effective pain management at the end of life hasten death or shorten life?

There are several published articles addressing this issue: Portenoy found no association with analgesic use and hastened death;<sup>10</sup> Walsh concluded that morphine does not cause chronic ventilatory impairment despite preexisting or concurrent respiratory disease in hospice patients;<sup>11</sup> Morita concluded that there was no association with patient survival and opioid/sedative use in terminally ill cancer patients;<sup>12</sup> and Good concluded there was no decrease in survival in patients receiving opioids or sedatives in the last 24 hours of life.<sup>13</sup> These articles suggest that the underlying disease causes death rather than the effective management of symptoms in the end-of-life setting.

Two professional societies have developed position statements regarding pain management at the end of life. The American Society of Pain Management Nurses (ASPMN) and the American Pain Society (APS). Their position statements follow:

#### ASPMN<sup>14</sup>

- Nurse uses personal/professional code of ethics characterized by respect for human dignity
- Do good and avoid harm
- Provide comprehensive and compassionate end-of-life care, including promotion of comfort, relief of pain, and at times, forgoing life-sustaining treatments
- Duty to benefit is adequate to support the use of increasing doses of opioids to alleviate pain, even if there may be life-shortening side effects
- Provide relief that is based on pain report and goals defined by patients and the health care team

#### APS<sup>15</sup>

- Terminal illness often accompanied by severe pain
- Pain and other symptoms can often be relieved, suicidal wishes are often linked to unrelieved pain
- Symptom control is often suboptimal because focus of care is on cure rather than palliation
- Policies to ensure adequate symptom management should take precedence over legalization of physician-assisted suicide (PAS) and euthanasia
- Health professionals must be protected to aggressively treat pain with drugs and terminal sedation when required

This article has dealt with different aspects of pain assessment at the end of life. Specifics regarding drug/opioid doses, implantable devices, and neurosurgical techniques are not addressed here but are adequately covered in a multitude of published materials.

## REFERENCES

1. Crawley L, Marshall P, Lo B, Koenig BA for the End-of-Life Consensus Panel. Strategies for Culturally Effective End-of-Life Care. *Ann Intern Med* 2002; 136:673-9.
2. Searight HR, Gafford J. Cultural Diversity at the End of Life: Issues and Guidelines for Family Physicians. *Am Fam Physician*, 2005; 71:515-22.
3. Last Acts, Means to a Better End: A report on Dying in America Today, November 2002. Available from Robert Wood Johnson Foundation from <http://www.rwjf.org/files/publications/other/meansbetterend.pdf>.
4. Wong, DL, Hockenberry-Eaton M, Wilson D, Winkelstein ML, Schwartz P. Wong's Essentials of Pediatric Nursing, ed. 6, St. Louis, 2001, p 1301.
5. Lefebvre-Chapiro L, Doloplus group: The Doloplus 2 scale-evaluating pain in the elderly. *Eur J Palliat Care* 2001;8(5):191-4.
6. Snow AL, Weber JB, O'Malley KL, Cody M, Beck C, Bruera F, et al. NOPPAIN: A nursing assistant administered pain assessment instrument for use in dementia. *Dement Geriatr Cogn Disord* 2004, 17:240-6.
7. Warden V, Hurley AC, Volicer L. Development and Psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) Scale. *J Am Med Dir Assoc* 2003, 4(1): 9-15.
8. Miaskowski, Cleary J, Burney R, Coyne P, Finley R Foster R, et al. Guidelines for the Management of Cancer Pain in Adults and Children. Glenview (IL): American Pain Society (APS);2005. 166p. (Clinical Practice guideline; no.3).
9. Swarm R, Angheluescu DL, Benedetti B, Cleeland C, Coyle N, et al. NCCN Clinical Practice Guidelines in Oncology, Adult Cancer Pain, Vol 1.2007. National Comprehensive Cancer Network. 2007. Available at [http://www.nccn.org/professionals/physician\\_gls/PDF/pain.pdf](http://www.nccn.org/professionals/physician_gls/PDF/pain.pdf).
10. Portenoy R, Sibirceva U, Smout R, Horn S, Connor S, Blum R, et al. Opioid Use and Survival at the End of Life: a Survey of a Hospice Population. *Journal Pain Sym Man* 2006; 32:532-40.
11. Walsh T, Rivera N, Kaiko R. Oral Morphine and Respiratory Function amongst Hospice Inpatients with Advanced Cancer. *Support Care Cancer* 2003;11:780-4.
12. Morita T, Tsanuda J, Inoue S, Chihara S. Effects of High Dose Opioids and Sedatives on Survival in Terminally Ill Cancer Patients. *J Pain Symptom Manage* 2001;21:282-9.
13. Good P, Ravenscroft P, Cavenagh J. Effects of Opioids and Sedatives on Survival in an Australian Inpatient Palliative Care Population. *Intern Med J* 2005;35:512-7.
14. American Society of Pain Management Nurses Position Statement on Pain Management at the End of Life, 2003. Available at <http://www.aspmn.org/Organization/documents/EndofLifeCare.pdf>.
15. Max M, Cleary J, Ferrell B, Foley K, Payne R, Shapiro B. Treatment of Pain at the End of Life, A Position Statement from the American Pain Society, 2007. Available at <http://www.ampainsoc.org/advocacy/treatment.htm>.



## Management of Gastrointestinal and Respiratory Symptoms in Palliative Care

---

By Priscilla F. Bade, MD

Pain is distressing, but is not the only symptom that causes misery for patients with life-threatening illness. Constipation, nausea, vomiting, lack of appetite, dysphagia, shortness of breath, cough, fatigue, delirium, depression and anxiety are other symptoms that need palliation. This article will overview symptom assessment in palliative care, and then, in more detail, it will address specific gastrointestinal as well as respiratory symptoms. Psychological symptoms are discussed in another article in this issue.

### **Symptom Assessment in Palliative Care**

To identify and treat symptoms effectively, assessment is important. History and physical examination are first steps. The history should include the nature and time course of the symptom, along with its severity and consequent effect on the patient's function and quality of life. Caregiver input

is also helpful, particularly if the patient is suffering from dementia or delirium. Careful inquiry about medication use (prescription, over-the-counter and alternative/complementary medications) and comorbidities may affect the diagnostic process and choice of treatment. Physical examination should be directed at identifying the cause of the symptom. Further investigation, including laboratory tests and radiological studies, may be performed if the results will cause a significant change in management.

It is important to discuss goals of care with the patient and family. The question should be asked: "Is our main goal at this time to keep this person alive as long as possible and as functional as possible while maintaining comfort, or is the main goal to preserve comfort and to allow a natural death?" In the early stages of a life-threatening illness,