
A Plan to Improve Pain Management for Dying Patients

A proposal by the Governor's Blue Ribbon Panel on Living and Dying With Dignity
Task Force On Pain Management in the Dying Patient, 1997

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Introduction

Dying is often accompanied by pain which is severe enough to make living unbearable. An interdisciplinary approach to the palliation of pain can, in most instances, bring sufficient relief and assure comfort and dignity during one's final days. This degree of pain relief should be available to all. To assure that it is, the following recommendations are made:

- That the Agency for Healthcare Policy and Research and American Pain Society guidelines for the treatment of pain be accepted as the standard of care for all healthcare providers.^{1,2}

- That the right to skilled pain management in the dying patient be included in the "Patient's Bill of Rights" at all DOH certified and/or licensed facilities.

- That the Department of Health be empowered and directed by legislation or executive action to use these standards in developing measurable, enforceable objectives by which the adequacy of pain management in those institutions and by those providers can be measured.

- That these measurements be carried out routinely as part of the DOH periodic reviews and that citations be issued to those failing to comply.

- It is the intention of the committee that the term "Cancer Pain" be broadened to include all patients dying with pain.

Minimum Standards

1. Evidence that specially designated caregivers are available to dying patients with pain who have been trained in pain control and who have the authority to administer this care.

2. That an assessment of pain be made part of the initial assessment of all patients dying with pain.

- *3. To assure optimal pain management, formal means should be developed and used within each institution for evaluating pain management practices and for obtaining patient feedback to gauge the adequacy of its control. The quality of pain management should

be evaluated in all settings where patients (with cancer) receive care.

- *4. The quality of (cancer) pain management should be evaluated at the points of transition on the provision of services (e.g., from the hospital to the home) to determine that optimal pain management is achieved and maintained.

- *5. For pain management to be effective, each practice setting should designate who will be responsible for pain management.

- *6. Policy and standard procedures, which define the acceptable level of patient monitoring and appropriate roles and limits of practice for health care providers, should govern the use of specialized analgesic technologies.

- *7. To ensure optimal pain management, formal means should be developed and used within each institution for evaluating (cancer) pain management practices and should include feedback regarding the adequacy of pain relief. Optimal pain management requires the interaction of all members of the health care team, including the patient. A formal process should be developed to evaluate the quality of management across all stages of the disease and across all practice settings.

(*Standards No.3 through No.7 are verbatim from the "Management of Cancer Pain"¹ page 143).

Institutions to be Monitored

1. Acute care hospitals
2. Skilled nursing/intermediate care facilities
3. Community based settings (eg. Residential care homes)
4. Hospice programs
5. Home health/home-care agencies

Other Recommendations

1. Problems exist in the referral practices Hospice Care and must be addressed. This includes the restrictive prognostication guidelines of "Six months of life or less" and therefore we recommend that the State of Hawaii mandate benefits for Hospice Care with a **one year or less** life expectancy.

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rounded by love. With the support of a hospice team, patients can die the same way. If the sages are to be believed, love is the only thing that goes with us into death.

Hospice care is generally delivered in the patient's own home. Many families worry that patients must be in the hospital for pain management to be effective. Although pain management is quite effective in the home setting, the less "technical" methods of administration of pain medication tend to work better in the home with family members as caregivers. A restriction hospices have been facing since the inception of the Hospice Medicare Benefit is cost containment. This restriction is also rapidly coming to the forefront in the hospital setting. In hospice, the pain must be effectively managed at the lowest possible cost, since reimbursement to hospices is given on a per-diem basis, with no consideration given to the particular treatments offered. In the home setting, the challenge is to keep the interventions "human scale." That means that in general highly technological interventions create much anxiety among lay caregivers. This concept is supported by the World Health Organization and the U.S. Public Health Service.⁵ By keeping the methods of medication administration away from the highly technical in the hospice setting, both the goals of reducing family anxiety and cost containment are met.

Transdermal fentanyl is an efficacious medication in the terminal setting. Its advantages include infrequent dosing, fewer side effects compared to PO opiates, ability to continue dosing when the oral route is not available (such as when death is imminent) and good control of pain. Hospices consider the relative high cost of this medication to be outweighed by its advantages. On the other hand, PCA pumps or other parenteral modalities can be intimidating to families in the home setting and are even more costly. On occasion PCA pumps are necessary, but use on a large scale would make it impossible for most hospices to operate within the financial constraints with which they must function.⁶ The proper use of adjuvant medications such as NSAIDs and/or steroids for bone cancer pain, and anticonvulsants or antidepressants for neuropathic pain along with the opiates can also be critical factors in the comfort and therefore quality of life during the endstage.

An often overlooked route of administration not only for opiates but other medications is the rectal route. Though PO administration remains the preferred route, the rectal route is a simple technique of administration with a comparable reliability of absorption and low cost as the oral route.⁷ The rectal route is also available when the patient can no longer swallow as death approaches. Most family members can be easily taught rectal administration.

Respiratory problems frequently require palliation in the hospice setting. Lung cancer is the most common terminal cancer diagnosis. Many lethal cancers tend to metastasize to the lungs. Radiation or chemotherapy may result in compromised pulmonary function. Ascites from abdominal cancers may contribute to dyspnea. Comfort is often restored with low dose morphine, anxiolytics, oxygen administration, steroids, possibly PO antibiotics in the case of pneumonia, and/or paracentesis for ascites.⁸

Other uncomfortable symptoms often addressed in the hospice setting include nausea and constipation. Fortunately medical management of nausea is a realistic goal today with the variety of effective medications available. Even difficult to control nausea often responds to "BDR" suppositories, consisting of Benadryl 25mg, Decadron 4mg, and Reglan 20mg.

References

1. Randal, J. Preparing for Life's End: Do More Health Professionals Need More Training? *Journal of the National Cancer Institute* 89(1)15-16.
2. Weissman, D., MD. Cancer Pain Education for Physicians in Practice: Establishing a New Paradigm, *Journal of Pain and Symptom Management* 12(6) 364-371.
3. Tuch, H., MD, Palliative Care: Finding Meaning at the End of Life. *Geriatrics* 51(12)12.
4. Griffie, J., RN, and Weissman, D., MD. Palliative Medicine Nurse Preceptorship at the Medical College of Wisconsin, *Journal of Pain and Symptom Management* 12(6) 360-363.
5. U.S. Department of Health and Human Services, Public Health Service, Agency for Health Care Policy and Research, Clinical Practice Guideline Number 9, *Management of Cancer Pain*. March, 1994.
6. Baumrucker, S., MD. Duragesic (transdermal fentanyl) in Hospice Care. *The American Journal of Hospice & Palliative Care*. Nov.-Dec., 1996.13-15.
7. Warren E., PharmD), Practical Use of Rectal Medications in Palliative Care, *Journal of Pain and Symptom Management*. 11(6) 378-387.
8. Kemp, C., RN, Palliative Care for Respiratory Problems in Terminal Illness. *The American Journal of Hospice & Palliative Care*. Jan. -Feb., 1997.26-29.
9. Doyle, D., MD, Palliative Care: Much More Than Terminal Care. *British Journal of Hospital Medicine*. 56(6)252.
10. Byock, I., MD, Developmental Milestones and Tasks at the End of Life, presentation at the NHO Annual Symposium, Washington, DC, October 20, 1994.

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2. Benefits for Medicare and Medicaid accepted pain management services (including but not limited to, surgical and/or radiation intervention) needs to be provided independently from the daily hospice coverage allowance.

3. Educational coursework in pain management should be encouraged and supported in the Continuing Education curricula at all DOH reviewed facilities for all licensed healthcare personnel.

4. Although it is recommended that pain management services be readily available and easily accessed, it is not the intent of this panel to legislate mandatory referral of patients to a "Pain Specialist." Through appropriate education and awareness of services already available, the patient's primary physician should be able to treat pain adequately. If the primary physician is unable to control the patient's symptoms, referral to the appropriate services (eg. pain management specialist, hospice, pain team, etc.) should be made.

5. We recommend that existing professional organizations be directed to develop standards for pain management and that they incorporate methods to assure quality in this area (eg. Peer review. Continuous Quality Improvement. Quality Assurance, etc.)

References

1. "Management of Cancer Pain", Clinical Practice Guideline Number 9. U.S. Department of Health and Human Services, Public Health Service, from the Agency for Health Care Policy and Research Publication No.94-0592, March, 1994, 257 pages.
2. "Quality Improvement Guidelines for the Treatment of Acute Pain and Cancer Pain". American Pain Society Quality of Care Committee Consensus Statement. *Journal of the American Medical Association*. December 20, 1995. Vol 274. No.23, 7 pages.

