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# Pain Management and Palliative Care in Hospice

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“There is nothing more we can do.” Every physician, nurse, and social worker hates to have to be the one to deliver the bad news when a disease has reached the terminal phase and when further curative measures are futile. No one wants to deprive the patient and family of hope. This is understandable. However, most patients know quite well what is going on. The experience of not being told frequently results in the patient’s feeling isolated. What patients often want is the simple truth and reassurance that their physician whom they have grown to trust, will not abandon them at the end.<sup>1</sup>

Fortunately, the statement “There is nothing more we can do,” is not a true statement. In fact, there is a lot we can do during this final phase of life to alleviate pain and suffering in all of its forms. The first step in helping the patient and family accept this potential palliation of suffering is for the professional community to fully understand all that can be done during the final months of someone’s life. We can indeed relieve pain and other uncomfortable physical symptoms. We can facilitate the completion of the “end of life tasks.” We can support the family in processing the loss they are about to endure, and we can help people in this stage of life reach their potential of a peaceful and natural completion of their life.

Everyone who has had serious pain fears pain. Our first responsibility to the terminally ill patient is excellent pain management. Traditionally, physicians’ attitudinal barriers to pain management have included fears of addiction and serious toxicity including respiratory depression, fears of the consequences of poor outcomes such lawsuits and fears of scrutiny by regulatory bodies.<sup>2</sup> Fortunately, in our community these factors are less of a problem among physicians than they are in many other places. Patients and families often seem to worry about addiction, however. In hospice care we will frequently differentiate between necessary medical use of opiates and addiction with such phrases as “An addict uses drugs to escape from life, you are taking the medication so you can better participate in your life.” Reassurance and differentiation between physical tolerance and addiction are often needed to encourage patients to take the pain medication as prescribed.

Many patients still fear abandonment during the terminal phase, and this often gets translated into a lack of confidence that their pain will be well managed until their death. Quality of life issues also surface and pain management is essential to quality of life. Increased incorporation of palliative care principles into medical practice is timely in light of the current public eye on quality of life during the endstage. To further this end, new training programs would be useful to help health care professionals improve these critical skills.<sup>3,4</sup> The public also needs to be educated to understand that comfort during the final stages of life is a reasonable expectation.

Constipation, a result of immobility, reduced PO intake of food

and fluids, and narcotic analgesia may be successfully treated with a wide variety of dietary measures, medications and treatments. There is also a place in symptom management care for complementary therapies such as application of superficial heat and cold, massage, acupuncture, healing touch, relaxation techniques, guided imagery, and distraction.<sup>5</sup>

The alleviation of suffering, paramount to excellent hospice care, means much more than effective symptom management. Indeed, in any setting, caring for those with suffering due to advanced disease, whether physical, psychosocial or spiritual, is best addressed by an interdisciplinary team of specially trained professionals.<sup>9</sup> Many hospitals today are also establishing palliative care units or creating palliative care teams that address suffering in all of its forms, even prior to the terminal phase of a disease. The interdisciplinary team is basic to hospice care. Teams consist of the patient’s own personal physician, and various hospice professionals including a Registered Nurse Case Manager, a Medical Social Worker, a Home Health Aide, a Chaplain, and specially trained volunteers. Together the team addresses, in addition to physical symptomology, the psychosocial and spiritual dimensions of suffering.

To address suffering in all its dimensions, Hospice Hawaii has begun a specialized program called *Na Hoa Malama* (Friends Who Care). This program is based on the work of Dr. Ira Byock, an emergency room physician and medical director of a hospice in Missoula, Montana. Dr. Byock identifies “developmental milestones and tasks at the end of life” that relate directly to the usual causes of non-physical suffering. Failure to complete these end of life tasks, in one way or another, is generally at the root of the non-physical suffering in the terminal phase. Dr. Byock says the tasks include reaching a sense of completion with worldly affairs, a sense of completion in relationships with community, a sense of meaning about one’s individual life, an experience of the love of self and of others, a sense of completion in relationships with family and friends, acceptance of the finality of life, a sense of a new self beyond personal loss, finding a sense of meaning about life in general, and a surrender to the transcendent, the unknown — “letting go.”<sup>10</sup>

Every patient is an individual and each has his or her own goals, agenda and abilities. Working with the patient’s own goals is essential in helping to facilitate the completion of this stage of life. The values of the patient and family determine how they perceive what is happening to them and helps to frame what they define as “suffering.” It quickly becomes obvious that the full interdisciplinary team is needed to guide a patient and family through and beyond their suffering. It can be done. Peaceful death is a realistic possibility.

We are born surrounded by our families and friends and sur-

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.<sup>5</sup> 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.<sup>6</sup> 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.<sup>7</sup> 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.<sup>8</sup>

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.

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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.)

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