Sr. Rosemary Ryan, M.M.S., M.D.

M.L., a sixty-one year old widow, has breast cancer that has metastasized to several bones resulting in significant bone pain, and to her liver with associated loss of appetite and occasional nausea. Her husband of forty years died suddenly one year ago and she is grieving his loss. She has been estranged from her only child for ten years, since her daughter married a man M.L. strongly opposed. Throughout most of her life she was active in religious practice but has been “angry with God” since her husband’s death and feels unable talk to God or receive spiritual consolation. Her husband’s death left her financially strapped and she is attempting to move into affordable housing.

The pain and suffering of terminal illness for M.L. has many facets: physical pain; discomfort due to nausea; grieving with reactive depression; the sorrow of estrangement from her daughter; anguish at her inability to touch God; financial challenges; and the impending loss of familiar surroundings. Truly effective care will require clinical skills to provide relief of physical symptoms, as well as psychosocial and spiritual supports to assist her in entering as fully as possible into the final part of life’s journey.

M.L.’s situation is unique, and yet not so dissimilar from that of many others who are in the last stages of their lives, suffering from illnesses that have poor prognoses. These individuals frequently experience pain and loss from many different sources. Those involved with their care are challenged to work with the “whole” person to provide skilled, compassionate care at the end of life.

We are gaining experience in knowing how to provide such care effectively. Over the last several decades, the modern hospice movement has affirmed that much can be done to ease the suffering of those who are terminally ill through skilled nursing, and psychosocial and spiritual supports for patients and their families, combined with
expert pain control and relief of other symptoms. In the United States, hospice has developed over the last twenty-five years mainly as a program to care for patients in their own homes or residential settings. Some hospice homes and facilities have also been opened to provide “hospitality” for those whose care cannot be managed at home.

Despite the overwhelmingly positive experience of patients and families who receive hospice care, referral to and acceptance of hospice services late in the course of illness continues to present a challenge to hospice care providers. Many patients do not begin to receive hospice care until death is imminent, in some cases when they are literally on their death beds. This is unfortunate, as patients and their families are thus deprived of valuable medical, social, and spiritual support to guide them at the end of life.

Prevailing cultural attitudes towards death and fears associated with end-of-life issues often cause patients and their families to postpone hospice care until the very end stages of illness. Similarly, there is often reluctance on the part of care providers to refer patients to hospice earlier in the course of disease, before it progresses to end stages. For some health care providers, referring patients to hospice can signify professional failure. These attitudes toward hospice are also due in part to the availability of so many interventions, which at times foster an unrealistic hope of prolonging meaningful life and which make it seem possible to defy death. In contrast, hospice approaches death as a natural part of the life journey, and allows patients and their families the opportunity to face death realistically.

**Palliative Care**

Over the past fifteen years, palliative care medicine has begun to emerge as a specialty. Palliative care consultation services and specialty units in health care facilities are rapidly being developed.

According to the World Health Organization, palliative care, which has its origin in the hospice movement, is:

... the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families ….

Palliative care:

* Affirms life and regards dying as a normal process.
* Neither hastens nor postpones death.
* Provides relief from pain and other distressing symptoms.
* Integrates the psychological and spiritual aspects of patient care.
* Offers a support system to help the family cope during the patient’s illness and in their own bereavement.¹

The growth of palliative care services offers hope for expanding the approach to end-

of-life care that is exemplified by hospice traditions and that is extended to patients throughout the course of illness.

**The Experience of Pain at the End of Life**

Uncontrolled pain due to terminal illness is a fear that many people share. This is not without cause, as too many people have witnessed family or friends experience unrelieved pain. Research studies confirm the prevalence of uncontrolled pain at end of life.\(^2\) There is also increasing documentation that the undertreatment of pain is more pronounced among those in minority groups, women, the elderly, and individuals with a history or suspicion of prior drug abuse, especially those who experience chronic pain due to illness.\(^3\) In addition, reports of physicians’ and nurses’ self-assessment confirm that medical professionals are often lacking in adequate skills to assess and appropriately treat pain.

The incidence of pain in patients with terminal illness due to cancer is significant. Pain significant enough to require treatment with narcotics occurs in approximately eighty-five percent of cancer patients as they approach the end of life. In other end-stage systemic illnesses, pain can be a factor, though it is often of lesser significance and frequently occurs in combination with other symptoms.

In nearly all cases, pain can be treated effectively to a degree that is acceptable to the patient. For most patients, medications, usually narcotics, are necessary. In some instances, radiation therapy or, in rare instances, surgical procedures may provide significant relief for specific types of pain.

For roughly ninety percent of patients, medications given orally, dissolved under the tongue, given in pill form, or dispensed in patches and absorbed through the skin provide adequate pain control.

Each of the following criteria is essential for pain management:

1. Careful assessment of the pain with appropriate history and examination to determine the type of pain(s), pertinent features, location(s), characteristics, etiologies, factors relating to exacerbation and relief, and effects of treatment.

2. A plan for treatment with careful attention to changes in the surroundings and alteration of movements which may cause or intensify pain.

3. Use of medications that provide adequate relief, employing the least potent medication that is effective. Ideally, medication should be administered in regular doses around the clock in order to prevent dips in the level of analgesia and a subsequent recurrence of pain. Standard treatment of persistent pain calls for long-acting medications that maintain a blood level over many hours, combined with short-

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\(^2\) The SUPPORT Principle Investigators, “A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT),” *JAMA* 274 (20) (November 22 1995): 1591–98.

acting medications as needed throughout the day for “break-through pain.” For moderate to severe pain, narcotics are most effective.

4. Careful consideration must be given to other treatments or medications that can complement the effect of the pain medications. This is pertinent especially when a patient experiences pain that is nerve or bone related. For instance, certain antidepressants or seizure medications are particularly effective in reducing pain that is nerve related.

5. Frequent reevaluation is necessary to assess effectiveness of treatment; to monitor any increase in pain due to disease progression; to respond to the development of side effects or new symptoms; and to adjust doses and medications as needed to continue providing effective relief.

Approximately ten percent of patients with pain related to terminal illness will require invasive techniques, most often narcotics delivered by a pump intravenously or under the skin. A video-cassette-sized pump can be worn much like a pocketbook, allowing free movement for a person who is able to be active. Anesthetic nerve blocks or medications delivered directly into the spinal canal are necessary in less than one percent of patients. In rare cases, the pain or agitation of terminal illness necessitates medication sufficient to achieve deep sedation in order for the person to reach a point of not being aware of pain.

Myths and Fears About Narcotic Use for Pain Management

More than twenty years of hospice experience in the United States and other countries provides evidence that consistent respect for a patient’s goals in conjunction with the ongoing and detailed assessment of his/her needs can achieve excellent results in providing comfort. In order to succeed in efforts to improve pain management, it is crucial to counter any myths and fears regarding the use of narcotics that might emerge during the course of a patient’s treatment.

1. Fear of addiction: The first and perhaps most prevalent myth is that the use of narcotics to manage pain will result in addiction. The fear of addiction, common among patients, families, and health care providers, is a frequent cause of undertreatment for patients who suffer acute and chronic pain, and is exacerbated by the heightened awareness of drug addiction in society.

However, it is a fact that when narcotics are prescribed for the legitimate purpose of treating pain, they essentially never cause addiction. In studies of addiction with a total population of over 24,000 patients, only seven could be documented as having become addicted as a result of receiving opioids for pain relief.4

It is necessary to distinguish addiction from physical tolerance and dependence. To some degree, a patient will develop tolerance to pain medication so that increased dosages are necessary to achieve the initial effect of relieving pain. However, in most cases, the more significant factor leading to increases in pain medication is the progression of disease, with a concomitant increase in the intensity of symptoms.

In addition, a patient will develop a physical *dependence* on pain medication over the course of treatment. As a result, the patient would experience physiological symptoms of withdrawal if the medication were stopped abruptly. However, with good pain management, this effect can be countered by titrating the dose of medication over several days until the dose is lowered or the medication discontinued when no longer necessary. Experience in hospice and palliative care confirms that in these situations the person remains comfortable and does not, in fact, develop a desire for more of the narcotic.

In contrast, *addiction* is a condition that refers to a psychosocial craving for narcotics or other drugs for reasons unrelated to the control of pain or discomfort, and includes a compulsive seeking on the part of a person to obtain the drug. There are some patients who experience pain due to their illness and who also have a history of substance abuse. While it is usually more difficult to manage pain to the patient’s satisfaction in these cases, it is possible to achieve acceptable pain relief safely. This requires careful balancing of the patient’s subjective assessment of pain and his or her demands, with the objective assessment of the patient’s functional response to the drug. When confronted with these situations, it is necessary for care providers to be attentive to the characteristic differences between genuine physical discomfort, and the emotional distress that is an underlying cause of addiction.

In light of these concerns, providing adequate doses of medication to bring about relief for patients constitutes a challenge for many health care providers. Many physicians, pharmacists, and nurses acknowledge both the need and desire for additional training in pain management in order to feel more confident in responding to the needs of patients.

Some physicians also fear that their attempts to provide appropriate doses of narcotics to manage pain effectively would lead to legal charges. While the absence to date of any legal action of this nature against physicians would seem to call this fear into question, this apprehension persists, with some validity. A 1997 survey of members of state medical boards indicated that only eighty-two percent considered it “lawful and generally acceptable medical practice” to prescribe opioids over an extended period for patients with cancer pain. The number fell to fifty-seven percent if the patient had a history of opioid abuse. These statistics again underscore the need for palliative care education for health care providers and regulators, as well as for the general population.

2. *The ceiling effect*: A second myth regarding pain management is the fear that a maximal dose of pain medication will be reached before the end stages of illness, leaving a patient without recourse for effective relief when pain symptoms intensify. In fact, there is no “ceiling effect” beyond which the major narcotics are ineffective. The doses of medication necessary to manage pain effectively are individual to each patient. In managing pain, it is important that attention be given to controlling side effects, using adjunctive medication, maximizing doses, and choosing the most effective route of administration on an individual basis.

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3. Confusion: Some patients fear the loss of mental acuity due to narcotics use. It is not uncommon for an older patient to express this as a “fear of losing my mind.” In countering this fear, it is important that physicians and care providers prepare the “opiate naive” patient for the possibility of experiencing some degree of confusion for the first several days of opioid use, with the assurance that this side effect usually passes as tolerance to that side effect develops.

4. Hastening death: Finally, many health care providers, including physicians, nurses, family members, and others involved with patient care, are reluctant to use narcotics for pain management because of concerns that the narcotics will interfere with breathing to the point of causing death. However, it is essential to understand that when doses are based on careful assessment of the patient’s need and titrated to that effect, they will not cause death.

To the contrary, there are situations in which the administration of carefully controlled doses of morphine affords great relief to persons suffering from marked respiratory distress. The morphine slows rapid breathing by relaxing the muscles, enabling the lungs to function more effectively by allowing oxygen exchange to occur more easily. This permits the person to breathe more comfortably.

Respiratory depression is rare in patients who have been receiving opioid treatment.6 Because many patients with cancer pain become opioid tolerant during long-term opioid therapy, clinicians’ fears that increased dosages will result in shortening the lives of patients are usually unfounded.7 Yet, as there are situations in which using narcotics to suppress pain might result in a suppression of consciousness, it is a concern that merits particular moral reflection and guidance. The Declaration on Euthanasia, published in 1980 by the Congregation for the Doctrine of the Faith, addresses this issue: “In this case, of course, death is in no way intended or sought, even if the risk of it is reasonably taken; the intention is simply to relieve pain effectively ….”8

Similarly, the Ethical and Religious Directives for Catholic Health Care Services, published by the National Conference of Catholic Bishops in 1995, provides more nuanced guidelines regarding difficult situations in which health care providers must respect the dignity of the person and sanctity of life, and ease suffering due to pain. The Directives state:

Patients should be kept as free of pain as possible so that they may die comfortably and with dignity, and in the place where they wish to die. Since a person has the right to prepare for his or her death while fully conscious, he or she should not be deprived of consciousness without a compelling reason. Medicines capable of alleviating or suppressing pain may be given to a dying person, even if this therapy may indirectly shorten the person’s life so long as

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8 The Sacred Congregation for the Doctrine of the Faith, Declaration on Euthanasia (1980), n. 6.
the intent is not to hasten death. Patients experiencing suffering that cannot be alleviated should be helped to appreciate the Christian understanding of redemptive suffering.

Managing Additional Symptoms

Other symptoms frequently associated with terminal illness can include: nausea and vomiting; constipation; incontinence; difficulty sleeping; depression; agitation; skin breakdowns; infections related to altered immune status; decreased appetite with weight loss; and others. A significant amount of effort goes into a plan of care that would prevent the development and/or progression of these and other symptoms. In addition, adjustments in treatment are made when and if new symptoms arise. Interventions are always designed to maintain or achieve a patient’s comfort and well-being. Although medications are a mainstay, these are used in conjunction with diligent attention to personal care, positioning, adjustments in diet and environment, providing education and explanation, offering psychosocial and spiritual supports, and offering complementary therapies when possible.

Palliative Care in Systemic Illness

In addition to cancer patients, hospice and palliative care services are important for many people who are in the end stages of chronic illness that is due to the failure of one or more bodily systems. These individuals account for many of the patients who are seen routinely by palliative and hospice care providers. Such patients might include those who are in the end stages of heart disease, dementia, stroke, liver or renal failure, lung disease, or any other debilitating condition that results in a state of terminal decline.

The advances of medicine in recent decades have resulted in marked improvement in capabilities for managing serious illnesses. These advances allow medical professionals to prevent—or at least delay—many life-threatening complications of systemic illnesses. Technical interventions such as mechanical ventilation, dialysis, and even organ transplants can prolong life to a remarkable degree.

Despite these advances, there comes a time in the life of each person when interventions to sustain or prolong life may become more burdensome for the individual than the benefit of the treatment. When a person arrives at this point, he or she may make the decision to shift the focus of treatment from aggressively seeking to prolong life to providing comfort and care.

The Ethical and Religious Directives for Catholic Health Care Services provides helpful guidelines in these situations:

A person may forgo extraordinary or disproportionate means of preserving life. Disproportionate means are those that in the patient’s judgment do not offer a reasonable hope of benefit or entail an excessive burden, or impose excessive expense on the family or the community.


Ibid., n. 57.
The goals of palliative care are equally as important for people with chronic systemic illnesses as they are for patients with cancer and other terminal illnesses. This is true throughout the course of illness, but is especially relevant as a person nears the end of life, as it is a time when hospice care can be particularly effective.

Although many people with chronic systemic illness are cared for by family members in a home setting, a significant number seek care in skilled nursing facilities or other residential settings. Palliative care, with hospice services available in the final months, can significantly improve the quality of life for this population. Sadly, this population is woefully lacking in effective care.

**Conclusion**

The experience of good palliative care, in a hospice program when appropriate, can significantly alter a patient’s perspective on life, especially in its terminal stages. B.T. is one such example.

B.T. ’s case was similar to that of M.L. (above) in that she had breast cancer with multiple bone metastases. Her adult children moved her into the area and arranged for care in our hospice residence. On the first visits of each team member (nurse, social worker, home health aide, pastoral care coordinator, and me, her new physician) she asked if we could just give her more morphine to “get it over with.” Each team member assured her that we would work with her to make her comfortable and support her and her family, but affirmed that the hospice approach was to neither hasten nor prolong death.

The hospice team soon learned that B.T. ’s main problem was not her “terminal cancer” but alcoholism, which had dominated her life for most of her seventy years. In the hospice setting, she was detoxified from alcohol, while pain and other symptoms were addressed. Newly sober, B.T. began to face life anew, consider what she had hoped for and where she felt she had failed—especially as a mother. Her children struggled with wanting to support her and with their anger towards her for being a mother who “had not been there” for them. Over the course of several months, B.T. and her children worked through the pain of their past and gradually came to know one another in a new way, ask for and offer forgiveness, express their gratitude, and to say goodbye. B.T. also tentatively reclaimed her spiritual roots.

Shortly before her death, I asked B.T. why she never repeated her initial request to “get it over with.” She quietly reflected, “I guess I found something to live for.”

B.T. ’s situation offers a typical example of the kind of support that hospice and palliative care offer to guide people through the end of life. In her particular circumstances, the skilled management of physical symptoms allowed B.T. to attend to other vitally important aspects of her life. The psychosocial and spiritual supports afforded B.T. the opportunity to embrace fully the final part of her life’s journey. This is exactly what skilled compassionate care at end of life can make possible.

It is a challenge to health care providers and to all of us as members of society to provide such opportunities along with the supports necessary to make them a reality.