

Managing pain in serious illness and at life's end

Pain is a symptom of many diseases. As a general rule, the presence of pain should lead to medical attention for evaluation and treatment. There are many different types of pain, many different causes and many different treatments. Fixing the underlying problem that has caused the pain is most important but is not always possible and even when it is possible, may take quite some time. Pain should be treated while waiting for the underlying cause to be remedied. The following information provides basic information about the treatment of pain in the hospital, especially in the setting of serious or incurable illness.

Are there deficiencies in pain management for seriously ill hospitalized patients?

Yes. The treatment of 9,000 seriously ill patients with diseases such as advanced cancer, heart failure or lung disease was evaluated at five major teaching hospitals in the United States. These patients were so ill that one-half died within six months of hospitalization and study enrollment. Findings about pain management in the hospital included: (1) 6 out of 10 patients reported moderate to severe pain at days 8 - 12 of hospitalization; (2) more than 50 percent of patients had serious pain the last three days of life; and (3) emotional suffering of patients, families and professionals was substantial.

Is this what patients want when facing serious illness? Is this what patients want if they might be at the end of life?

Different patients have different tolerances for pain. Some persons are insensitive to pain and believe that pain is simply to be endured. While such an attitude may sometimes be admirable, in very serious illness, simply "toughing it out" can be both physically and psychologically harmful.

Untreated pain can interfere with treatment of the underlying illness. This is especially true at the end of life. This may sound like common sense, but it is common sense backed up by scientific study.

In one study, 340 seriously ill patients were asked to rank the most important quality care factors near the end of life. The number one quality of treatment goal for these patients was freedom from pain. The next most important goal was peace with God. Other top 10 goals included presence of family, having financial affairs in order, resolving conflicts, feeling life was meaningful and dying at home.

In another study, 126 patients with kidney failure, HIV (AIDS) or living in a long-term care facility also ranked pain and symptom control as their most important goal, followed by avoiding prolonged dying.

Facing an incurable illness is bad enough. Poorly treated pain only makes it harder to face and can keep the patient from living as well as they can and meeting other important goals.

What are some of the ways that pain can be treated in this setting?

As already mentioned, trying to fix the underlying cause of the pain whenever possible is always important. For example, if there is a tumor causing pain and physicians can treat it effectively with medication, surgery or radiation, this not only may extend the patient's life, but also can make the pain go away in many cases.

Whether the underlying cause can be fixed or not however, there are many ways to treat pain. If pain is mild, it may need nothing more than simple medications that anyone can purchase over the counter. Complimentary therapies including stress reduction techniques and meditation can be helpful for some patients.

However, when pain is most severe, strong pain-relieving medications known as opioids (sometimes referred to as narcotics) are needed. There are many opioids available to treat pain. Some common opioids are hydrocodone, oxycodone, hydromorphone, morphine, fentanyl and methadone. Depending upon the drug and the patient's condition, opioids may be given by mouth, by injection, or by placing the medication directly on the skin.

Aren't opioids bad for a patient? Don't they cause addiction and do more harm than good?

There are many common misconceptions about opioids, including the misconception that they are highly addictive. These misconceptions can sometimes keep doctors or nurses from giving adequate dosages of these most important medications and sometimes keep patients from taking the pain medicine when offered. The reality, however, is quite different.

In a large study of 12,000 hospitalized patients who received at least one opioid preparation for moderate to severe pain, only four cases of addictive behavior were found. In another study

of 550 cancer patients who experienced pain and were treated with morphine for a total of 22,525 treatment days, there was only one case of addiction.

DO OPIOIDS HAVE SIDE EFFECTS?

Yes. All medications may have unintended side effects. Opioids are no exception. Among the most common are drowsiness, confusion, nausea and constipation. The drowsiness and confusion usually resolve without intervention. On occasion the dose may need to be changed or a second drug may need to be added. Nausea can be treated with an anti-nauseant, but as with drowsiness or confusion, it often resolves without other intervention. Constipation is the most common side effect of opioid pain medications and so laxatives are commonly ordered at the same time the pain medicine is ordered.

BUT AREN'T OPIOIDS DANGEROUS?

Any drug, especially if used improperly, can be dangerous. Simple aspirin is associated with bleeding problems, sometimes severe, and aspirin is believed to lead to 7,000 to 8,000 deaths a year. Acetaminophen (Tylenol), another common non-prescription medicine, can cause serious liver injury and even death. In the proper hands, opioids are the safest and most effective pain relieving medicines available, especially in the setting of serious illness with severe pain.

DO OPIOIDS HASTEN DEATH?

No! One of the most common misconceptions about opioids is that they hasten death. Because opioids are often given to seriously ill patients, including patients in the last chapter of life, it may appear that they hasten death. However, careful study has demonstrated that when properly used, opioids do not make death come sooner. This has been our experience at Baylor as well. In fact, if a terminally ill patient is left in severe pain, their death may come sooner as a result of the stress of severe pain. Living in a bed of pain is not only psychologically harmful, it can be physically harmful as well.

ARE HIGH DOSES OF OPIOIDS USED TO “PUT PEOPLE TO SLEEP” AT THE END OF LIFE?

The dose of opioid used for a particular patient is dependent upon many factors, including pain intensity, drug metabolism issues and much more. The stage of the patient’s illness and the goal of treatment is also most important in determining how high a dose of pain-relieving medicine is needed. Physicians and nurses always seek to use the lowest dose needed of all drugs. With opioids, the lowest effective dose will be used in an effort to minimize side effects such as drowsiness or confusion. However, in the setting of very severe pain, high doses of opioids leading to sedation may sometimes be needed. Near the end of life, continuous sedation with high doses of opioids and other medications may be necessary, allowing the patient to sleep peacefully until death. This is referred to as “palliative sedation” and Baylor has policies and protocols regulating this process.

THAT SOUNDS LIKE HOSPICE? ISN’T HOSPICE JUST ABOUT DYING? DOESN’T HOSPICE SHORTEN LIFE?

Hospice seeks neither to prolong nor shorten life, but rather to maximize treatment of symptoms associated with the last chapter of life. Hospice may be associated with longer survival in some cases. A study of 4,493 Medicare patients suffering with congestive heart failure or cancer of the pancreas, lung, colon, breast or prostate and with one or more markers for terminal stage disease revealed that mean survival was 29 days longer for patients enrolled in hospice compared to those not on hospice. In a study reported by the Center to Advance Palliative Care and conducted at the University of Michigan, palliative care in patients with advanced cancer who received hospice-type treatment lived on average 39 days longer than those who received customary treatment.

(www.capc.org)

Where can I get help with pain management?

Baylor’s medical and nursing staff is dedicated to both cure and comfort. Your primary doctors and nurses can effectively treat most pain. Please let them know about any pain you are experiencing. In more complex or difficult cases, physician and/or nurse specialists in pain management are available. The sickest patients often have complex pain and other troubling symptoms. Their families may be under great stress as well. In these cases, the multidisciplinary palliative care team may be called in to assist. The goal of the palliative care team is to improve symptoms and help the patient and family cope with the illness, living as fully as possible and planning for the future. A hospital is usually not the best place to live fully and our palliative care team may assist the patient and family in transition to home, with or without hospice. In other cases, the patient may be so ill that going home is not possible. If death must happen, the palliative care team will be there to support and guide the patient and family through.

For more information about pain and symptom management, ask your doctor or nurse for referral to the pain management or palliative care service.