The Art and Science of Palliative Care

By Randolph Fillmore

In the world of palliative care, taking the time to listen is an important part of the health care spectrum provided to dying patients. At the Betty Jane & Creston G. Tate Foundation Chesapeake Hospice House in Linthicum, Md., School of Pharmacy palliative care resident Megan Potter (right) spends time with patient Joyce Brown.

PHOTOGRAPH BY MARSHALL CLARKE

When Elizabeth Kübler-Ross published her now-famous *On Death and Dying* in 1969, she emphasized the quality of life for terminally ill patients. She encouraged palliative care—pain and symptom relief—during the last days of the terminally ill instead of attempts at heroic cures. Because Kübler-Ross wanted better quality of life for the dying, she also championed the concept of hospice care, a model for medical and spiritual care focusing on the quality of remaining life.

First pioneered in England in the early 1970s, the hospice movement took its name from a place of shelter for weary travelers. Over the last 30 years, hospice care has become not only a concept, but a place where terminal cancer patients could have their pain relieved, find meaning in their last days, discover the time and comfort to interact with their loved ones, and have the final, and perhaps most difficult leg of their journey through life, made less lonely.

Once on the fringes of orthodox care, the science and the art of palliative and hospice care is now a respected field, and training in palliative care has an important place on the health care landscape.

The University of Maryland School of Medicine (SOM) initiated a mandatory junior-year rotation in hospice and palliative care, and students at the University of Maryland School of Pharmacy take a battery of courses in palliative care and pain management. The program is unique in pharmacy education and students come to the School of Pharmacy from across the nation and around the world seeking specific training in the pharmacology of hospice and palliative care. The School also offers one of the nation's first and few pharmacy residencies in palliative care.

The instructional design of a mandatory palliative care education program for junior-year students first took root at the School of Medicine with a 1994 education grant from the National Cancer Institute (NCI).

"Hospice and palliative care were neglected areas in health care professional training," recalls Douglas Ross, MD, a medical oncologist and the principal investigator of the NCI grant. "This neglect was compounded by the fact that there were few formally structured programs in palliative care available to students. Hospice is now recognized as an important and effective means of achieving palliative care and improving the remaining life for terminally ill patients. Our program was designed to produce physicians who could provide such care and do this by integrating state-of-the art hospice and palliative care practices into academic medical instruction."

Because there can be little quality to the end of life if pain is not effectively managed, pharmacy students are focusing on the role of the pharmacist. They also learn about the attitudes and conflicts in the care of the terminally ill and examine current social ethical issues in death and dying.

"All pharmacists, whether or not they work in hospice care, should have knowledge of palliative care," says Mary Lynn McPherson, PharmD, who teaches palliative care and pain management to pharmacy students. "That's why we designed this program. Across the board, the University of Maryland has risen to the challenge by instituting training in palliative care in medicine, pharmacy, nursing, and social work."

Palliative care recognizes that dying is not simply an isolated, clinical event. It covers many kinds of care: managing disease symptoms, including pain; managing adverse events; and managing end-of-life social issues. Attention to the physical, psychological, social, cultural, and spiritual issues of the patient and family are included. Palliative care even recognizes the stresses on the professional caregiver.

"Spiritual issues are important for the patient and family and do not go unaddressed in palliative and hospice care," says Deborah Shpritz, PhD, RN, project director for palliative care education at SOM. She plays the role of the hospice nurse in mock interdisciplinary team meetings when students present their hospice cases at the end of their rotations.

"Our junior-year students are asked to describe their attitudes and feelings before meeting their patients and then assess how these feelings may have changed after the experience," explains Shpritz. "The rotation is often a profound experience for students who may be confronting the mortality of others, and perhaps their own mortality, for the first time."

She recalls that one student suddenly realized that she had not grieved for her own father, who died several years before.

"The student was caught up in medical school," recalls Shpritz. "She put her grief on a back burner and she was not expecting it to surface in the course of this rotation."

Medical student Barbara Robinson also had a life-changing experience while on her rotation, preceded by the terminal prognosis of a family member.

"I had never heard of hospice care before starting medical school," says Robinson. "But just 2 days before I started my hospice rotation, my 31-year-old cousin was admitted to an in-patient hospice with metastatic colon cancer. She had been very angry about her prognosis. But when I saw her at the hospice, she appeared happy, comfortable, and at peace." She adds, "On my hospice rotation, I spent the afternoon with a 67-year-old woman and she, too, was comfortable. Now I see hospice as the preferred option. It's a great concept."

As part of their coursework in caring for the terminally ill, pharmacy students visit a funeral home to explore some of the behind-the-scenes realities of death. They also participate in a course called *I Can Cope*, designed to prepare them as facilitators in the *I Can Cope* series. The course was developed by the American Cancer Society (ACS) for implementation at the society's Baltimore Hope Lodge and other locations where community interest is keen, including hospitals and support groups. The ACS's 16 Hope Lodges nationwide serve as havens for cancer patients in treatment and their families. The unique program in Baltimore gives pharmacy

students hands-on experience with cancer patients and their families.

"*I Can Cope* is a series of educational programs for people with cancer," explains McPherson. "One must be trained as a facilitator to lead a session, and ours is the first example of pharmacy students being trained as facilitators—they have been able to empower patients to ask for good pain management."

Pharmacy students Doug Bradford and Marilyn Matthews made a presentation at the Baltimore Hope Lodge and found that their talk was effective and well-received by patients and their families.

"We talked with them about a wide-range of pain management issues," says Bradford. "From relaxation techniques to addressing some of their preconceived notions about taking pain medications."

"There are a lot of myths surrounding opioids," notes Darwin Liu, also a pharmacy student. "We were able to dispel some of those misconceptions."

When a patient is in the terminal stages, there is concern that not enough morphine is used to palliate the worst pain. Effective pain control allows the patient the time and comfort to draw life to a close in a dignified manner.

"Controlling pain is therapeutic," explains Timothy Keay, MD, who guides students through the School of Medicine's rotation.

There are times when a change in pain treatment is required, and this is one area where the palliative care pharmacist can shine, suggests McPherson.

"Switching from morphine to methadone can be tricky," warns McPherson. "There is not a linear relationship between the two. Methadone is more potent and other variables have to be taken into account."

To illustrate, she relates the story of a dying patient who wanted to be switched from a cumbersome intravenous morphine pump to oral methadone so that she could go on a final family vacation to Ocean City. The switch worked, the patient enjoyed the vacation, and remained on her oral medication.

According to McPherson, pharmacy students get a good handle on doing pain assessments with their patients by asking about the quality of the pain and providing adjectives that patients can use to describe their pain—such as electrical, throbbing, shooting, or dull.

> **"Students find that spending an hour with someone, holding their hand, just listening, is very therapeutic."**

A full assessment also includes gathering information on what initiates pain, its severity (perhaps on a scale of 1 to 10), where the pain is localized, and what measures have already been taken to try to ease it.

"It's a great advantage for the pharmacist to be able to determine if the patient is having neuropathic pain, " says McPherson. "There are drugs that work preferentially on nerve pain."

So that the right drugs are being used to manage the pain, Keay concurs with the importance of identifying the kind of pain patients may experience.

Offering Keay an assessment of her hospice patient, medical student Kim Fredrickson reported that her patient experienced shooting pain (perhaps neuropathic), and suggested that the pain might come from spinal cord compression.

"This is difficult to treat directly with morphine," suggests Keay. "The patient may not have this pain until he tries to move, then BANG!"

Pain dominates discussions when the pharmacy students discuss palliative care.

"Everyone is afraid of dying, and nobody wants to face it," observes pharmacy student Marilyn Matthews. "I think what people fear most is dying in pain, and with our pharmacology knowledge, we can help empower them to make decisions."

The pharmacist's role in palliative care does extend to education, McPherson explains. "Helping people to become knowledgeable about their drugs empowers them and gives them a role in their care."

Medical students completing their rotations offered stories of their impact on patients that could not be measured in descriptions of pain reduction or milligrams of medications. Just time spent with patients—listening—seemed therapeutic.

"There is truth in the concept of the 'therapeutic self,'" says Shpritz. "Just by talking with patients, clinicians can do a lot. Students find that spending an hour with someone, holding their hand, just listening, is very therapeutic."

When she went with a hospice nurse to visit a recently admitted patient who had suffered a massive stroke, pharmacy student Laura Tolen discovered that words of compassion can help families, but that compassion can also be expressed without words.

"His wife was so anxious she couldn't sit down. She kept pacing the kitchen," recalls Tolen. "But, as the hospice nurse spoke with her, her anxiety calmed. Words can make a difference."

Sitting alone with the dying man who could not move or speak, Tolen also found that their eye contact and her presence seemed to ease his journey.

For pharmacy and medicine students who will go on to work with the dying, Keay promises them a rewarding career.

"I've worked with hundreds of dying patients," says Keay. "It's very challenging, but extremely rewarding. Done well, palliative care and hospice are good medicine. If you do palliative care well, people are so grateful."