Death and Dying

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PROLOGUE

Caring for the terminally ill patient is a necessity and a challenge for any pharmacist but can be exceptionally intimidating to the pharmacy student. Exposure to topics such as “Death and Dying” helps prepare the student to provide not only clinical expertise but also emotional support to these patients and their families. The following article covers points I stress to the student, including pain management, stages in death and dying, the pharmacist’s role in hospice care, the place of spirituality in healthcare, and the pharmacist’s role in counseling terminally ill patients. By introducing these topics in the classroom and at the externship sites, the student will be better prepared to comfortably help the dying patient and their families deal with death.

RATIONALE

Pharmacy students are generally able clinicians but often lack the expertise needed to effectively counsel the terminally ill patient. This is a necessary learning experience lacking in many curricula.

Several years ago, during a hospital externship weekly class meeting, my students shared experiences gleaned from making rounds and visiting patients in their hospital rooms. A few students reported that they “freaked out” when they saw patients with tubes sticking out of them, comatose and semiconscious. These comments again reminded me that our students and many of us in hospital pharmacy practice relate simply to chart orders or prescriptions from our computers. The patient is merely a name and a bed number.

At that time, I began to explore the possibility of introducing to my students the concept that our patients are real. I dedicate one session during the four weekly externship sessions to the concepts of death and dying. This session is divided into the following components: pain management and comfort measures, stages in death and dying, the pharmacist’s role in hospice care, the place of spirituality in healthcare, and the pharmacist’s role in counseling terminally ill patients and their families.

PAIN MANAGEMENT

Managing pain and providing comfort are two important aspects in caring for the terminally ill patient. Often the clinician must go beyond conventional protocols to accomplish this goal. The clinician must keep in mind that pain control is the ultimate goal. They must be ready to address concerns over dosage ranges, addiction potential and side effects.

The student is introduced to the overall concept of pain management. Discussions relating to the impact of pain on patients and their families are incorporated into our interactive death and dying project. Students are made aware of the impact of pain on quality of life issues relating to the patient’s physical, social, spiritual and psychological wellbeing. Good pain control can contribute immensely to the achievement of all the above.

As an example, to familiarize the class with pain management, each student is presented with a prescription order for a terminally ill patient. The prescription is for morphine sulfate, 15mg/cc, SIG: 1cc IM q4h prn pain. The patient is in severe pain, agitated and screaming for her injection of morphine. The patient’s last dose was two hours ago. The questions to the student are: what do you do with this order? Do you want to fill the order? What alternatives can you recommend to the ordering physician?

Options that are presented by the students are discussed among the class. The students are instructed on techniques such as changing the frequency, enlarging the dose, adding a medication to act as a potentiating agent, and the option of a morphine drip or a PCA pump (the uses and programming of a PCA pump are introduced).

DEATH AND DYING

The extern must realize that death is not a static process. Elisabeth Kübler-Ross, a pioneer in caring for dying patients, identified five stages that the terminally ill patient goes through: denial, anger, bargaining, depression, and acceptance(1). Recognizing and understanding these five stages can help pharmacists and caregivers relate to their patients. Students must also realize that some patients do not go through the stages in sequential order. To expose the students to the stages of death and dying, they are given several case studies from dying patients and asked to identify what they feel the patients are experiencing.

An unexpected observation during my own pharmacy practice was that patients who had a colostomy, ileostomy, or mastectomy appear to go through these same five stages. They were mourning the “death of a body part.” This was born out in my own personal experience. When I had chest pains and was diagnosed with a blocked coronary artery, I was faced with two options: open heart surgery or angioplasty. Luckily, I was able to have the angioplasty, but during the time of diagnosis and months after the angioplasty, I exhibited all the stages described by Kübler-Ross and remember having to work through each stage separately.

It is extremely important that new pharmacists be able to communicate with terminally ill patients and those who have lost body parts or who have changed their body image. We must listen to and acknowledge the patient’s fears and concerns, while showing that we care and are concerned with their well being.

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HOSPICE CARE

Hospice care is an important facet in the care of terminally ill patients. One goal of hospice care is to make the patient and family comfortable during their final days. This is achieved by addressing the physical, spiritual, emotional and social needs of the patient and family. Pharmacists can contribute their special training (i.e., pain management skills) to the hospice team.

During their rotation, students are given the opportunity to visit dying patients at the hospital. Visits to a local hospice unit are also encouraged. This allows the student to witness first hand the dying process and how this process affects the patient, family and friends. They can observe and participate in providing excellent, compassionate care to the patient.

In our group discussions, I share with the students that being in touch with their own feelings will enable them to be more empathic with the dying patient. I stress the importance of allowing the patient to talk or not talk about what is going on and acknowledging the patient’s fears and concerns. In most cases, knowing there is someone there will be a comfort to the patient and the patient’s family. Through these experiences, there is opportunity for the student to grow personally as well. The student needs to be made aware that the dying process can be very painful for them as well as the patient.

During discussions with my students, I urge them to examine their own fear of death. Understanding this enables the student to more effectively communicate and empathize with the patient and family. Fear of death reaches much further into our lives than our conscious minds are willing to confess. In considering their own death fears, students can investigate and adopt positive views. One such view is offered by David Viscott who wrote, “when you say you fear death, you are really saying that you fear you have not lived your true life. This fear closes the world in silent suffering, yet by seeing through the fear you can turn it into a positive force. Let your fear of death motivate you to examine your true worth and to have a dream for your own life.”

To further reinforce these points, students are broken up into small groups and are asked to share with each other their own experiences with a dying family member or friend. In addition, the students are asked to share with their classmates their own fear of death. After group discussion, the class comes together to share various cultural and religious beliefs regarding the dying process. Different ways of celebrating and mourning death are shared in the class, enabling the students to become more aware of the differences that occur in various religions and cultures.

SPIRITUALITY

Students must clearly understand that death is both a natural and spiritual process. According to David Lason, a psychiatrist and president of the National Institute for Healthcare Research in Rockville, Maryland, there are a growing number of people who are ill who would welcome some care of the soul along with chemotherapy or post-operative treatments. A study by Daaleman, et al.(2) measured what patients really want from doctors, and concluded that 77 percent wish physicians would consider their spiritual needs, while 48 percent said their physicians should pray with them.

Although the phrase has become a cliché, people have the right to expect “death with dignity.” We in the health professions need to find ways of contributing to this with terminally ill patients who are in great physical pain.

I am convinced that we still are not good at the clinical and spiritual care of the dying patient. Many physicians and pharmacists maintain that losing a patient means failure. They tend to feel that high technology and saving lives is a much more interesting challenge than the care of a patient who is dying. The point to emphasize is that the greatest challenge is to take excellent care of a dying patient. It is not easy. It takes sensitivity to the patient’s emotional and spiritual needs, as well as clinical expertise. Death can be a very profound and even fulfilling event for a family, and even for us as health professionals if we allow ourselves to get close enough to it and take part in a meaningful way.

In my class, to emphasize the full spectrum of patient’s needs, students are asked to read the following letter in class and to discuss how they would respond if it were sent to them by one of their patients. The letter emphasizes the fact that many patients are not only striving for medical help but are asking and searching for spiritual and emotional support.

Dear Lorraine and Mel,

By the time you receive this letter I will have embarked on a new journey into healing my body and my soul. The news of the recurrence of my lymphoma, (and a strain that is more aggressive) was not easy for me to hear. I trust my doctor’s advice that immediate treatment with chemotherapy is necessary. My commitment to be an active participant continues to be tremendously important to me. That includes diet, and all other therapies that support the immune system and nourish the physical body, as well as the spirit. Norman Cousins’ latest book, “Head First” (The Biology of Hope) reinforces my views(3).

I am blessed with a loving and supportive husband, children, family and friends. Offers of “what can I do?”, “I want to be part of your healing” have touched my heart, and though it is not easy for me to ask for help, I believe I have found a way to tap into the love and support you are willing to give me.

Several months ago the publication “BRAIN MIND BULLETIN” discussed the power of prayer in healing, even over long distances. The article described a study, which presented evidence that patients who had family and friends praying for them healed better and faster than other patients. (The evidence indicated that group energy was the most powerful.) Because I believe in a universal power it is my intention to create a HEALING CIRCLE to gather all the positive energies that you have to offer: Golden Healing Light, Unconditional Loving Support, Joy or Prayer, in whatever manner is comfortable for you to give it.

I will sit quietly with an open welcoming heart every day from 5 to 5:30 PM (California Time) as part of my daily meditation. If you are able to contribute your thoughts or prayers on any given day for a few minutes during that time, I will be here to receive your light, love and healing energies.

I will take one day at a time. Some will be very difficult. Still, I see this as another chance...an opportunity to turn my life around once more, and I am willing and ready to meet the challenge.

With love,
Leslie

COUNSELING THE TERMINALLY ILL

The pharmacist has a unique and challenging opportunity to interact with the terminally ill patient and their families...
when dispensing medications. The pharmacist’s communication skills with these patients are extremely important. Many pharmacists are uncertain what to say, and as a result, will not say anything for fear of saying the wrong thing. The pharmacy profession is becoming more involved with AIDS and cancer patients both in and out of the hospital setting. With increased contact with terminally ill patients, we have come to realize that there are no easy or standard methods for communicating with dying patients.

To emphasize this dilemma, much of our class time is spent studying how various cultures and religions celebrate or mourn death. The knowledge and skills gained allow the student to prepare counseling strategies that acknowledge and respect the patient’s beliefs. In this manner, we can ultimately help to ease the patient’s fear.

The students are given tips on counseling terminally ill patients and their families. Then, they are placed into a triad. One student acts as the pharmacist, the second student role plays the patient or family member and a third student acts as an observer, critiquing the counseling technique. The roles are rotated giving each an opportunity to play all three roles. I encourage students to get in touch with their own feelings without judgment of themselves. The triad is given permission to talk about fears and concerns in each of their triad roles. If the student is fearful discussing their fears and concerns in class, I invite them, if they choose, to see me privately.

One assumption we tend to make is that death is some-how unnatural, and, by implication, evil. We must discourage this type of thinking if we are to be successful at helping patients deal with dying.

**SUMMARY**

In recent years, I have been heartened by the way the subject of death and dying has opened up through such pioneers as Elisabeth Kübler-Ross. Looking deeply into the way that we care for the dying, Elisabeth Kübler-Ross has shown that with unconditional love, and more enlightened attitudes, dying can be a peaceful, even transformational, experience. What do I hope to achieve in these classroom sessions? I hope for more enlightened views of death and care for the dying. This will reflect on how we look at life and our care for the living. In my opinion, there is a reason for everything. Perhaps at the moment an event occurs, we have neither the insight nor the foresight to comprehend the reason, but with time and patience, it will come to light.


**References**

