
Palliative Care Education – a Growing Need

by Norma Wylie

The establishment of palliative care as a viable part of medicine will only be accomplished if it is included in both nursing and medical school curricula. Such education needs to include an examination of issues of disclosure and issues of pain and suffering.

Physicians, health care professionals and society need to shift from cure-oriented treatment plans to care-oriented ones when cure is no longer an option. The first arena for such change is undergraduate medical education.

In a 1997 address to the Southern Illinois University School of Medicine graduating class, Dr. Joycelyn Elders, former United States Surgeon General, said, "you'll face a lot of problems when you leave the walls of this wonderful institution. The scientific foundation has never been brighter, but our practice and delivery lag far behind." Dr. Elders spoke of social and health problems that prevent many from receiving quality health care. One of the issues she emphasized relates specifically to our thesis on care: "Let me tell you, when you go in to see a patient, nobody cares how much you know until they know how much you care, and don't you ever forget that. You've got to care enough to be concerned about the problem: more than concerned, be committed to getting something done about it and getting it solved."

Palliative medicine, as it has evolved from the hospice movement, founded in 1969 by Dr. Cicely Saunders, has the potential for providing a higher quality of life for Americans during their dying and death (Saunders 1995). Hospice has given us many of the tools needed as we expand the scope of palliative care, not only for the terminally ill cancer patients dying in hospice, but for those dying in hospitals, nursing homes, and at home.

The World Health Organization defines palliative care as "The active total care of patients whose disease is not responsive to curative treat-

ment. 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 quality of life for patients and their families." The major challenge to this new model of treatment — palliative care — is the focus in the health care environment on cure. Much of medical education, treatment plans for the health care team, and expected outcomes for patients has focused on cure. But for thousands, cure is no longer an option. This is the challenge, then: to define quality of life and explore how it can be achieved for dying patients in the midst of a cure-oriented, death-denying society.

The word "care" has not been fully understood in the context of the cure/care issue. Henri Nouwen explains that the word "care" finds its roots in the Gothic word *kara*, which means lament (Nouwen 1974). He invites us to share someone's pain by being present (touch their inner wound) with a gentle and tender hand

"Caring" is the principal challenge for each of us, whatever our specific role is as caregiver. Physicians should be able to say to patients, "I can no longer cure you, but I will always care for you." Physicians, I believe, have the responsibility to begin the open communication process between themselves and their patients. The physician is the captain of the team. They do not, however, have to do this alone; they should involve staff and family members. This teamwork, while requiring commitment, compassion, and courage, provides great satisfaction for the members of the team.

Early in this century, many people died at

home. Dying took place in the presence of the family, and children experienced it as part of the normal life cycle. Daily living went on with no secrets or game playing. There was less fear and mystery about death than exists today. The pendulum has swung dramatically; today less than twenty percent of our population die at home. Between fifty-five to sixty percent die in hospitals, ten to fifteen percent in other institutions, and ten percent in nursing homes. These figures indicate the need for palliative care in order to provide some quality of life during the end stages of life, with more emphasis on living than on dying.

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Medical and nursing education programs have a responsibility to include in the curriculum training and education on how to deal with end-of-life care issues such as: "What does dying mean to you?" Before health care workers can help others, they need to find answers for themselves. Only then can they walk the journey with fellow humans.

Issue of Disclosure

Disclosure is a major issue in palliative care education. To tell or not to tell? Dr. Elizabeth Kubler-Ross believed that the question shouldn't be, "Should we tell?" but rather, "How do I share this with my patient?" Members of the Project on Death in America, in discussing a "peaceful death," emphasized the importance of communication between physicians and patients. They believe physicians need to play an active role in educating the public and in answering questions (Morris 1996). Telling the dying patient and family the truth may be an ethical issue concerning the rights of each individual, but dying patients

deprived of truth are deprived of opportunities for living.

Jory Graham's landmark book, *In the Company of Others: Understanding the Human Needs of Cancer Patients* (Graham 1981), is for all professionals and lay citizens trying to make our world a better place in which to live and die. The crusade she began for the rights of those confronted with illness and disease speaks to those in the delivery of palliative medicine, those who are trying to provide care when cure is no longer possible. In a chapter on a patient's right to know, she recommends medical students be asked, when taking their final pledge, "Where are medical ethics when, by withholding or limiting truth, a doctor so alters reality for both patients and their families that they are utterly confused?" Further, she says, "When truth is gone, everything is gone."

Issues of Pain and Suffering: Physical, Emotional, Social, and Spiritual Components

There are several components related to pain and suffering. Physical pain usually demands immediate attention. As health care professionals face the totality of a patient's suffering, however, there are more subtle and complex components to be included if we choose a holistic approach to care. These are emotional, social, and spiritual. These four components of pain are inter-related, affecting each other as we plan to keep the patient as pain free as possible to enable some quality in his/her living.

Physical Pain

To be a practitioner in palliative care requires knowledge and understanding of pain and symptom control. This demands collaborative practice. Betty Ferrell wrote, "Staff education is critical to effective pain management, as professionals simply cannot practice what they do not know. We should strive to make knowledge of cancer pain relief mandatory for all medical and nursing staff. It should also be included in the curriculum for medical and nursing students" (Ferrell 1994). Ferrell also believes that patients must be involved in efforts to achieve pain relief. She advocates

giving patients written material that can reinforce the verbal information they receive. And warns health care givers about moral responsibility: "The failure to deal with relief of pain adequately is no less than a social disgrace. We must remain not only dedicated clinicians and scientists but also moral agents as we seek to revolutionize the treatment of pain!"

Pharmacology has been in the curriculum for medical and nursing education for years. However, the precise meaning of P.R.N.s needs to be carefully explored by health care givers so they can knowledgeable and responsibly treat patients' pain. There is unnecessary fear that over medicating can lead to addiction. A careful titration of morphine dose against the individual patient's pain must be administered until pain control is achieved. This allows the patient to be involved in the management of his own pain and more in control of his own living.

Emotional and Social Pain

Pain is not simply a physical sensation. Illness causes anxiety, fear, anger, and depression. This lowers the patient's pain threshold, which affects pain management. Communication skills are needed to assist the patient in expressing feelings. These include touching, listening, and caring by the physician, the caregiver, and the family. It is important to help the dying patient try to express his/her fears and feelings. Truth telling in this exchange is paramount. Also important to the patient's sharing is the presence of a good listener who has the caring attributes, as discussed by Nouwen in *Out of Solitude*. Feelings can be worked through if they can be expressed to someone who understands and is not frightened by anger, tears, or silence. Patients' fears may concern the family, also. They, like the patient, have a journey, and love and support may be needed along the way. Families need explanation of the patient's progress, pain, and symptom control, as well as discussion of the actual process of dying.

Spiritual Pain

Some of the feelings just described as emotional pain are also present as spiritual pain —

suffering. Understanding suffering in the context of palliative care is essential if we are going to give total care to the patient and his family. Ira Byock raises ethical and moral questions surrounding spiritual pain, emphasizing that each person's own faith and religious beliefs influence the meaning of suffering for that individual (Byock 1994).

To understand the meaning of suffering, we must journey with those who suffer, but we must also enter into our own pain. Victor Frankl wrote, "If there is a purpose in life at all, there must be a purpose in suffering and in dying. But no man can tell another what this purpose is. Each must find out for himself" (Frankl 1984).

Being willing to share suffering by entering into someone's pain can be the occasion for a healing relationship of love and acceptance. One way to enhance this relationship is through prayer. This was a very important component of the hospice established by Saunders. Hospital chaplains should be integrated members of the team, developing a plan of care and providing guidance when care givers ask for help. Respect for the beliefs and practices of all people is essential in the practice of palliative care.

In discussing the four components of pain control, it is important also to acknowledge that staff members may suffer, depending on how closely they worked with the patient and how involved they were with the patient and family. Denying their feelings hinders growth in learning to deal with their own pain and inhibits their ability to work with others in the future. Doctors, too, are not immune to feelings of pain and loss and should be encouraged to find a way to share those feelings with an understanding person.

Through teaching medical students and training health professionals about issues of quality of life, truth telling, engendering hope, pain and symptom control, positive changes will occur from cure-oriented treatment to care-oriented, when cure is not possible. As we approach the twenty-first century with more of us living longer, health care professionals and members of the

community, not just physicians, need to accept the challenge of finding ways to enhance life as we encounter the changes associated with aging. Palliative care — providing care when cure is not possible — deserves priority attention as our health care systems and medical schools begin these new journeys.

References and Additional Reading

- Butler, Robert, Robert Burt, Kathleen Foley, June Morris, and Sean Morrison. 1996. "Palliative Medicine: Providing Care When Cure Is Not Possible." *Geriatrics* 51(5) (May):33-44.
- Butler, Robert, Robert Burt, Kathleen Foley, June Morris, and Sean Morrison. 1996. "A Peaceful Death: How to Manage Pain and Provide Quality Care." *Geriatrics* 51(6) (June):33-42.
- Byock, I. 1994. "When Suffering Persists." *Journal of Palliative Care* 10:2. Summer.
- Cousins, Norman. 1989. *Head First: The Biology of Hope*. New York: E.P. Dalton.
- Ferrell, Betty. 1994. "An Institutional Commitment to Pain Management." *APS Bulletin*, American Pain Society (April/May):16-20.
- Frankl, Victor E. 1984. *Man's Search for Meaning*. New York: Washington Square Press.

- Graham, J. 1981. *In the Company of Others*. New York: Harcourt Brace Jovanovich.
- Kubler-Ross, Elizabeth. 1969. *On Death and Dying*. London: MacMillan.
- Miller, P. 1997 "Struggle." *Bioethics Forum* 13(1) (Spring).
- Nathanson, David. 1992. "Physician Learns a Lesson from a Dying Patient." *American Medical News*.
- Nouwen, Henri. 1995. *Our Greatest Gift: A Meditation on Dying and Caring*. San Francisco: Harper Collins Publishers.
- _____. 1974. *Out of Solitude*. Notre Dame, IN: Anc Marin Press.
- Nuland, Sherwin B. 1994. *How We Die: Reflections on Life's Final Chapter*. New York: Alfred A. Knopf.
- Saunders, Cicely, Mary Baines, and Robert Yunlop. 1995. *Living and Dying: A Guide to Palliative Care*. Oxford University Press.
- Siegler, E. and F. Whitney, (Eds.). 1994. *The Nurse-Physician Collaboration*. New York: Springer Publishing.
- Wylie, Norma. 1988. *The Role of the Nurse in Clinical Medical Education*. Springfield, IL: Southern Illinois University School of Medicine.
- Wylie, Norma, Terrill Mast, and Jay Kennedy. 1996. *Sharing the Final Journey*. Hartsport, Nova Scotia, Canada. The Robert Pope Foundation.