
Educating Nurse Leaders in Ethics and End-of-Life Care

by *Melanie Simpson*

The Midwest Bioethics Center's Nursing Leadership Institute 1999 focused on leadership in ethics and end-of-life care. Twenty-four nurses attended the four-day retreat, during which national speakers, community experts, and Center staff facilitated the continuing education of nurse leaders dedicated to improving end-of-life care in their communities. All participants in the Institute agreed to design and implement a community project for their constituency. Project reports will be made prior to the next nursing leadership institute. This article examines the role of nurses in providing end-of-life care.

Before we had a language for "palliative" or "end-of-life" care, people simply took "good" care of their dying family members and friends, usually in their own homes. Many, perhaps most, caregivers had little or no experience or education in caring for the dying. Instead, compassion sufficed. Then, however, an era of technology began that completely changed the focus. Suddenly, the purpose of care was different; it had shifted from keeping the patient comfortable and allowing death to occur naturally to using technology "to cure the patient at all costs."

Now nurses and other health care professionals are bringing the focus back to the patient's bedside. They are trying to swing the pendulum back to a happy medium in which diagnosis and treatment are included in care planning, but comfort and compassion are the ultimate goal.

Understanding End-of-Life Care

End-of-life care is no longer a simple affair. Approximately 75 to 85 percent of the population dies in hospitals, nursing homes, or other institutions (Wylie 1997). With so many logical and technological interventions among current treatment options, ethics plays a major role in any course of action. Being prepared to deal with ethical issues fosters patient and family well-being, and protects nurses' integrity (Scanlon 1998). It

also entails the need to better educate our patients, families, and health care professionals.

Educational Opportunities for Nurses

Nurses lack opportunities for education on end-of-life care. According to a recent study, only 2 percent of the overall content and 1.4 percent of the chapters in nursing texts relate to end-of-life issues

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(Ferrell 1999). And yet nurses spend more time at the bedside of dying patients than do other professionals. Nurses are also the largest group of health care professionals represented on hospital ethics committees. Participation on these committees is a source of knowledge and skills that nurses can use to help patients and peers in ethical decision-making (Schroeter 1996). However,

nurses are also looking for continuing education programs to provide information in ethics and end-of-life care — information that they did not receive during their formal or on-the-job training.

Three years ago, Midwest Bioethics Center acknowledged the need to change the focus of its Nursing Leadership Institute to concentrate on leadership in ethics and end-of-life care. In 1999, twenty-four nurses from six states, attended the four-day retreat. Goals of the program were to provide continuing education and information, inspiration, and ongoing support to nurse leaders dedicated to improving end-of-life care in their respective communities. The program was held amid rural autumnal surroundings, October 19 to 22, in Linwood, Kansas, at the Tall Oaks Conference Center.

The program encouraged nurses to examine their professional role in improving care of seriously ill and dying patients. National speakers, community experts, and Midwest Bioethics Center staff spoke and facilitated discussion on eighteen issues in the four-day period.

National Speakers

The following national presenters were among the faculty at the Nursing Institute:

- Linda Wrede-Seaman, MD, Medical Director for Providence Hospice of Yakima in Yakima, Washington, and author of *Symptom Management Algorithms: a Handbook for Palliative Care* spoke on Pain and Symptom Management in Palliative Care and Using Symptom Management Algorithms. Each attendee received a copy of Wrede-Seaman's book, and her presentation detailed its use in daily practice.
- Valerie Yancey, RN, CCRN, PhD, working at Barnes Jewish Hospital College of Nursing and Allied Health in St. Louis, Missouri, presented the concept of Holistic Nursing: End-of-Life Care for the Whole Person. Yancey explained the clinical significance of the mind/body connection, interpersonal energy, and the spiritual dimension of pain and suffering and

identified nursing skills and interventions relevant for holistic care at the end of life.

- Alicia Super, RN, BSN, President of Pain and Supportive Care Services in Portland, Oregon, presented the results of a Focus Project in Palliative Care, a program showing the inadequacies in many current efforts for quality improvement in end-of-life care.
- Alice Cornelison, RN, PhD, of Howard University, Washington, D.C., spoke on Nursing Ethics, End-of-Life Issues, and Cultural Diversity. Cornelison defined culturally competent nursing care and identified institutional practices to impact cultural competence among staff.

Community experts

Members of the local community were also well represented on the faculty:

- Teresa Long, MD, University of Kansas Medical Center, discussed Depression in Terminal Illness and stressed the importance of psychological/psychiatric symptoms at the end of life.
- Charlotte Cook, RN, BSN, CRNH, NorthCare Hospice & Palliative Care, Inc., explained Hospice Reimbursement and Benefit Concerns by describing covered services under the Medicare Hospice Benefit. She also facilitated a very helpful role-playing exercise to show the basics of hospice care.
- Beth Villines, RN, BS, CCRN, Saint Luke's Northland Hospital, shared the Spiritual Assessment form that she has developed for her institution and encouraged attendees to verbalize their own spiritual ideas, beliefs, and values.
- Julie Russell, RN, MA, nurse dramatist, performed a dramatic presentation of *Nick and Sheila and the World* (a video), which identified social and cultural factors that influence a patient's self-care behavior and access to the health care system.

- Tom Jacobs, recording artist and composer, performed an evening of reflective music in which he sang and told stories to show how music can be used for learning and healing.

Midwest Bioethics Center Staff

In-house members of the faculty included the following:

- Robert Potter, MD, FACP, PhD, provided our historical overview, treatment orientation, and palliative care models. He identified historical problems regarding death in America and traditional responses to these problems while suggesting outcomes for hospice/palliative care.
- Helen Emmott, RN, BSN, BA, discussed the evolution of nurse leaders in ethics as evidenced by developments in nursing ethics in the last two decades and explored ways for developing nurses as leaders in ethics in the future.
- Rosemary Flanigan, CSJ, PhD, presented "Ethics 101: Palliative Care Ethics," she defined ethics and distinguished it from morality, religion, law, and professional codes of ethics.
- Myra Christopher, the Center's president and chief executive officer, discussed organizational ethics and distinguished it from clinical and business ethics. She also used case examples to reflect organizational and clinical dilemmas and the role nurse leaders can play. Christopher also shared "The Spice Box," a story about her mother and herself that had originally appeared in *Bioethics Forum*. This story portrays patients and family members foremost as moral agents.
- M.C. Sullivan, RN, MTS, JD, discussed the "Ethics of Legal Concerns or How to Do the Best Job Possible and Alleviate Worry." She identified the ethical principles that support legal behavior in end-of-life care and ways to apply the legal principles that define the duties of nurses in implementing good palliative care.

Sullivan also led a discussion following the video presentation of "The Vanishing Line." She asked attendees to think about their values in relation to case studies presented in the video.

- Linda Johnson, ACSW, presented her view of communication with the patient and family, and identified the skills, benefits, and obstacles for effective end-of-life communication.

A Milestone for the Institute

The concept behind Midwest Bioethics Center's Nursing Institute was presented at a "Best Practice Conference" in October 1998. It has thus been recognized as an effective model for moving theory into nursing practice. Each of the nurses nominated to attend the Institute has an obligation to carry out a community project that is based on improving end-of-life care. Some previous projects have

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included introducing pain management as a required course at a nursing college and hosting a large conference on Palliative Care issues. As a result of their participation, many nurses return to their organizations prepared to help instill policies and guidelines promoting palliative care.

Participants at the Institute learn and share a vast amount of information in a very relaxed setting. They share more than facts as they walk the grounds of the conference center, eat together, and sleep in a dormitory-style building. And they leave behind excellent evaluations. Some of their comments, for example, describe the value of the Institute on personal and professional levels:

- [I will] "personally incorporate more holism in my nursing practice."

- "This has been the best conference I have ever attended in over twenty-five years of nursing."
- "The diversity, enthusiasm, and knowledge of all the speakers was incredible!"

Midwest Bioethics Center will repeat the Institute in October 2000. The theme for this year is "Providing Palliative Care in Chaos." The national faculty has already been chosen; participants will be nominated in July and August.

Conclusion

Facilities across the country have sent their nurse leaders to this Institute to have them bring back current relevant information on ethics and end-of-life care. The model for the Institute evolved from a consideration of the basics in nursing ethics in the hospital setting to include ethics and end-of-life care across the spectrum of nursing. Nurses from every area of nursing practice can enrich their personal and professional lives from this experience. Away from the sometimes cold

environment of the hospital and the daily strain of work, this retreat provides nurses with education, support, solidarity, and faith in their mission to care for the ill.

Further, the Institute teaches nurses how to be leaders in the community. These nurses will be leaders in end-of-life care and the movement to increase the role of comfort and compassion in health care.

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