

Humanities: Art, Language and Spirituality in Health Care

Series Editors: Christina M. Puchalski, MD, MS, and Charles G. Sasser, MD

Arts and Humanities in Palliative Nursing Education

Betty Ferrell, PhD, MA, FAAN, FPCN, Rose Virani, MHA, RN-C, OCN, FPCN, Hollye Harrington Jacobs, RN, MS, MSW, Pam Malloy, MN, RN, OCN, FPCN, and Kathe Kelly, RN, BSN, OCN

Division of Nursing Research & Education (B.F., R.V., H.H.J., K.K.), Department of Population Sciences, City of Hope, Duarte, California; and American Association of Colleges of Nursing (P.M.), Washington, DC, USA

Introduction

“~Nursing is an art: and if it is to be made an art, it requires an exclusive devotion as hard a preparation, as any painter’s or sculptor’s work; for what is the having to do with dead canvas or dead marble, compared with having to do with the living body, the temple of God’s spirit? It is one of the Fine Arts: I had almost said, the finest of Fine Arts. ~”¹

Florence Nightingale

Florence Nightingale, recognized as the founder of professional nursing, is credited as an early voice acknowledging nursing as an inherently artistic endeavor. Many nursing leaders have subsequently described the practice of nursing also as an intimate endeavor in which nurses care for patients at the most private and stressful times of life.

Nowhere is this more important than in the area of hospice and palliative care, where nurses provide seriously ill patients and their family members with care that addresses physical, psychological, social, and spiritual needs.²

Because nursing is an intrinsically artistic endeavor, as well as a scientific practice, the education of nurses in formal academic programs and through continuing education for those in practice can be enhanced through inclusion of arts and humanities.

Arts and Humanities in the ELNEC Project

The End-of-Life Nursing Education Consortium (ELNEC) is an international, continuing education, train-the-trainer program preparing nurse educators to integrate palliative care in undergraduate, graduate, and continuing education programs. Detailed information about ELNEC is available on the website (www.aacn.nche.edu/elneec).³ The ELNEC project has curricula/projects including ELNEC-Core, Critical Care, Pediatric, and Geriatrics, and the latest curriculum initiated in 2010 is the ELNEC-Veterans project, creating a nursing education program specific to institutions serving veterans.

Since 2001, the ELNEC project has trained over 11,000 nurses through 69 train-the-trainer programs representing nurses from all 50 states and from 65 countries. In each of these courses, arts and humanities have served as valuable means of educating nurses.

The artwork in Figs. 1–4 are examples of illustrations used in the ELNEC curriculum and were created by an artist, Connie Rose,

Address correspondence to: Betty Ferrell, PhD, MA, FAAN, FPCN, Division of Nursing Research & Education, Department of Population Sciences, City of Hope Medical Center, 1500 East Duarte Road, Duarte, CA 91010, USA. E-mail: bferrell@coh.org

Accepted for publication: November 18, 2009.

who worked closely with the ELNEC investigators to create these beautiful illustrations to capture key issues in palliative nursing. The inclusion of art, poetry, film, narrative, drama, and other means enables the faculty to teach the “art” of palliative nursing, which can be summarized in the following themes.

Illness as Human Experience

There is an abundant body of research that has confirmed that changing practice is much more than simply improving knowledge through didactic lectures. Adult learning is far more likely to occur, and to be retained, when learners engage multiple senses and when they are moved to a new understanding by engaging emotions, self-reflection, hearing stories, and being in touch with thoughts and experiences that are often repressed.

The arts and humanities are invaluable in palliative nursing education for each of the above reasons. One of the key goals in the ELNEC education is to remind nurses that illness is a profound human experience. In the Pediatric ELNEC training, the *Lion in the House* videos (<http://www.lioninthehouse.com>) are used to bring into the classroom the voices and images of ill children, their siblings and parents.⁴ These profound images remind us that first and foremost, the patient is a person. Reading poems or narratives written

by patients are also valuable in helping nurses to listen carefully to the words to hear the story of the person.

The Nurse-Patient Relationship

One of the key goals in the ELNEC training is to focus on the unique contributions of nurses in palliative care. Nurses recognize that while our care is interdisciplinary in nature, there is much to be learned about the nurse-patient relationship.

A number of teaching methods used in ELNEC are derived from the arts and humanities to address this area. One of the basic skills essential to the nurse-patient relationship is through role play in which nurses are taught to listen silently as their role play partner speaks of a loss they have experienced in their lives. This simple five-minute listening exercise can be a profound recognition of the value of “being” with patients, rather than only “doing.”

Another effective resource has been use of the film “Evan Mayday’s Good Death” in our ELNEC Critical Care training (<http://www.med.umich.edu/nursing/EndOfLife/mayday.htm>).⁵ This film was produced by a nurse, Linda Stodtman, RN, PhD, also an ELNEC trainer, and tells the story of a man who makes the decision to discontinue his ventilator support when his life quality was perceived to be unacceptable following years as

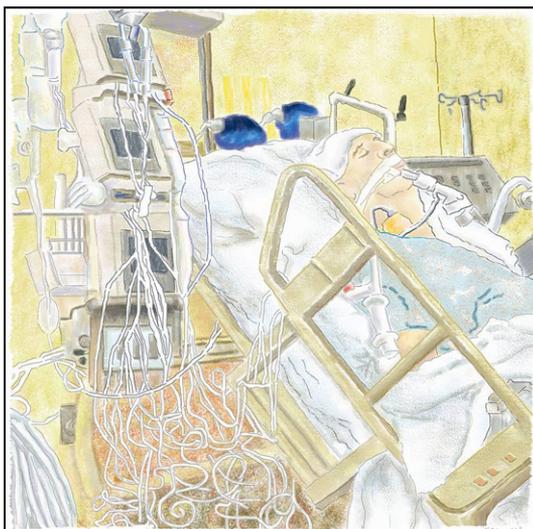


Fig. 1. Illness as Human Experience.

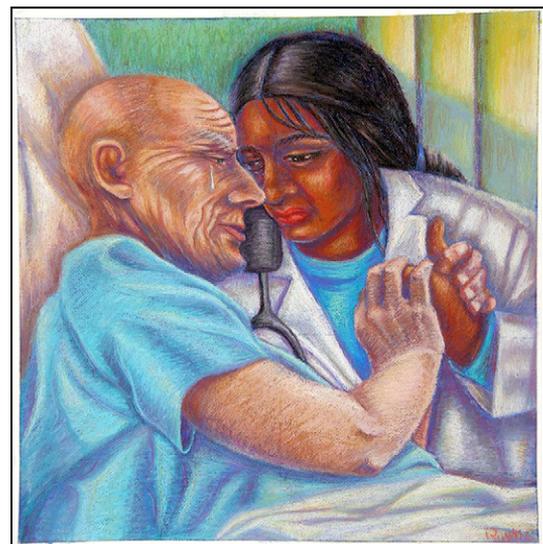


Fig. 2. Nurse-Patient Relationship.

a paraplegic after an accident. The film beautifully tells the story of his end-of-life decision through interviews with his wife and beautiful photos of Mr. Mayday throughout his life as a paraplegic and as a person who is ventilator dependent. Most profound, however, are the very honest interviews with his nurses, physicians, and other caregivers as they describe their struggle in supporting Mr. Mayday and his wife as he makes the decision to die. The use of film, photography, and other resources help nurses to vividly see the importance of the nurse-patient relationship in palliative care.

The Sacred Work of Palliative Nursing

Nurses attending ELNEC training often arrive at the courses both physically and emotionally drained from their daily lives and work. They often share their frustration in attempting to provide compassionate quality care amid staffing shortages, budget cuts, and ever increasing demands to document care, an increasing severity of illness in their clients, and the pressures of the workday to accomplish even basic care. During the ELNEC courses, it is common for nurses to “unwind,” to connect with their like-minded colleagues and to be reminded that their work is sacred. Through self-reflection exercises, journaling, film, role play, and other means, nurses often say that they remember why they became nurses and they again recognize their worth.

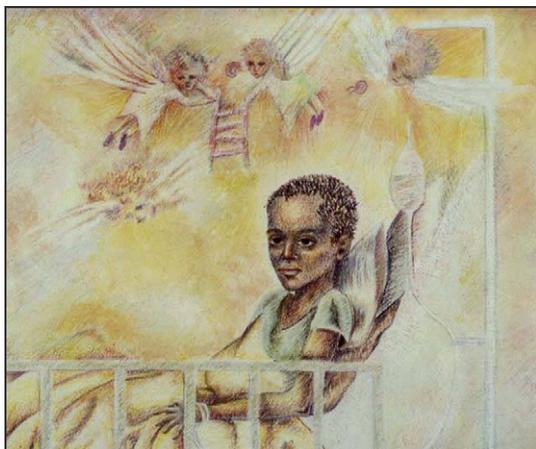


Fig. 3. Sacred Work of Palliative Nursing.

In response to course evaluations, a session has been added in the courses on “Self-Care.” In this session, nurses do a self-care assessment/reflection and also discuss in small groups ways that they care for themselves and also support their staff. This self-care session concludes with reading together a poem, *Grace*.⁶

Grace

Give me the **grace**

To care

Without neglecting my needs,

The **humility**

To assist

Without rescuing,

The **kindness**

To be clear

Without being cold,

The **mercy**

To be angry

Without rejecting,

The **prudence**

To disclose

Without disrespecting my privacy,

The **humor**

To admit human failings

Without experiencing shame,

The **compassion**

To give freely

Without giving myself away

—Source unknown

Suffering

Nurses often come to ELNEC courses seeking increased knowledge to enhance their skills in pain management, symptom control, bereavement support, or other “technical” aspects of care. Once immersed in a community of other palliative care nurses and a safe environment for sharing their experiences, it has been found that the case discussions, breakout sessions, and questions often center on the



Fig. 4. Suffering.

existential aspects of end-of-life care and on the suffering of patients and families.

While many narratives about nurses are powerful depictions of unique circumstances, most are instead profound in their simplicity. Nurses' work actually resembles that of ordinary people enduring very stressful circumstances. A nurse in the fullest sense relates to suffering people with an authentic and gentle approach.⁷ A caring nurse offers calm to terrified parents in a neonatal intensive care unit, assurance to the family awaiting the outcome of a surgery, hope to the patient receiving a first dose of chemotherapy, and a consistent presence to the patient in long-term care.

While literature and the media often create a negative and inaccurate portrayal of nurses, there are some fictional portrayals of nurses that capture the essence of care. One such portrayal is found in *Range of Motion*, a novel by Elizabeth Berg.⁸ This novel is a story of Jay, a man who becomes comatose after being hit in the head by melting ice that falls from a building. Jay is transferred to a nursing home, and while most of his family and care providers have little hope for his recovery, his wife Lainey remains optimistic. She works continuously to maintain Jay's dignity while she waits, ever present, for his awakening.

One evening, Lainey returns to the nursing home and the nurse, Wanda, suggests that Lainey may want to lie down in the bed next to Jay. The story continues told through Lainey's eyes:

"Just let me do something first," Wanda says. She moves to the side of Jay's bed, pulls down the sheet. He is on his side, and she removes the pillow supporting him, holds him over with one hand while with the other she reaches for the bottle of lotion on his bedside stand. She's proud of the way Jay's skin has held up, no bedsores yet. She squirts some lotion into one hand, closes the bottle again and puts it back on the bedside stand. Nurses are good at this kind of thing, using one hand for things that normally require two. And if you get one like Wanda, you can see the caring along with the skill. She rubs Jay's back with strong, circular strokes, and I watch, spellbound. There is a mesmerizing quality to watching someone do almost anything with care: tailors in their dry-cleaner windows, hunched over sewing machines. Bakers making art out of frosting. Children with a new pack of crayons and fierce intent. We are meant to use what we have, whatever it is. We are meant to be less mindful of our insides, more outwardly directed. That's what I think, as I watch Wanda rub Jay down, as the minty smell of the lotion makes its way over to me. There is incredible value in being in service to others."⁸

One of our most valuable teaching resources used in our ELNEC Pediatric training has been the film "Turning Toward the Morning."⁹ This film presents three cases including the death of a young child in a car accident, a suicide of a young adult, and the deaths of a father, mother, and infant from AIDS. The film is particularly poignant in its artistic expression of these stories, told not in spoken words but through visual images, photographs, and music. In the absence of words, nurses view this film with great focus on the images that are powerful.

Use of this film, as well as the other uses of arts and humanities that evoke strong feelings, must be followed with time for discussion and debriefing, as these artistic expressions often lead to intense feelings by the nurse participants. We also are attentive to participant needs, for example, in cases where participants may need individual attention if these experiences evoke strong emotion, unexpressed grief, or other responses. Another exercise

used in our Pediatric ELNEC has been a "From the Heart" art exercise in which nurses' journal and create pictures on a heart, writing a message to a child or family they have cared for. The hearts are then placed together in a collage with other heart drawings, illustrating the shared community of pediatric nursing in palliative care. The use of arts and humanities to touch the hearts of participants must be met with responsible support by course faculty. This is especially important because many participants are attending the course alone, far away from their usual support systems.

Summary

The depth and breadth of palliative nursing care is advanced through integration of arts and humanities in our education. Nursing students and novice through expert practicing nurses benefit greatly from these experiences and we believe that they are better prepared to practice nursing, the finest art.

References

1. Nightingale F. Notes on nursing, what it is, and what it is not. New York: D. Appleton and Company, 1860. Available from <http://digital.library.upenn.edu/women/nightingale/nursing/nursing.html>. Accessed October 1, 2009.
2. Coyle N. Introduction to palliative nursing care. In: Ferrell B, Coyle N, eds. Oxford textbook of palliative nursing, 3rd ed, Chapter 1 New York: Oxford University Press, 2010.
3. The End of Life Nursing Education Consortium (ELNEC). Available from www.aacn.nche.edu/elneec. Accessed October 1, 2009.
4. Bogner S, Reichert J. A Lion in the house [Motion picture]. Lion in the House videos. Sherborn, MA: Aquarius Health Care Media, 2006. Available from <http://www.lioninthehouse.com>. Accessed October 1, 2009.
5. Strodtman LK, Goode Giacomazzam M, Mann SL. Evan Mayday's "good death:" Teaching health professionals collaborative care. [Motion picture] 2006;. Available from <http://www.med.umich.edu/nursing/EndOfLife/mayday.htm>. Accessed October 1, 2009.
6. Anonymous. Grace. Available from <http://www.bellaonline.com/articles/art38074.asp>. Accessed October 1, 2009.
7. Ferrell B, Coyle N. The nature of suffering and the goals of nursing. New York: Oxford University Press, 2008.
8. Berg E. Range of motion. New York: Berkley Books, 1995.
9. Pickard C, Pickard A. Turning toward the morning: Stories of love & loss, of grief & hope. [Motion picture] 2003. Available from Rites of Passage, P.O. Box 226, Vanderpool, TX 78885. <http://ritesofpassagejourney.org/turning.htm>. Accessed October 1, 2009.