Teaching Strategies from the ELNEC Curriculum

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MAJOR EFFORTS AIMED AT IMPROVING CARE AT THE END OF LIFE AND PROMOTING A PEACEFUL, RESPECTFUL DEATH ARE IN PLACE ACROSS THE UNITED STATES. In recent years, funding to study and improve end-of-life care has totaled millions of dollars, with the Robert Wood Johnson Foundation taking the lead in funding numerous initiatives for educating health professionals. Among the Robert Wood Johnson initiatives are SUPPORT, a study to understand preferences for outcomes and risks of treatment, The End of Life Nursing Education Consortium (ELNEC), and the Toolkit for Nursing Excellence in End-of-Life Transition.

The End of Life Nursing Education Consortium (ELNEC) is a train-the-trainer educational program that helps nursing faculty integrate care of the dying patient and the patient’s family into the nursing curriculum. This article presents pedagogical techniques derived from the ELNEC teaching module on communication and key content areas for developing communication skills in end-of-life care. Competent end-of-life nursing care begins with an understanding of communication techniques and their potential impact on care.

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The nursing organizations represented by the ELNEC Advisory Board are working toward a collective, professional approach to the improvement of nursing care at the end of life. In 2000, the group released the ELNEC curriculum, developed by project consultants with extensive contributions by the Advisory Board and reviewers. The curriculum is a “train-the-trainers” course. It is expected that those trained in the ELNEC curriculum will be vital forces in its dissemination.

The course is designed as a three-day program. Nine modules, presented in didactic and interactive training sessions, address the critical aspects of end-of-life (EOL) care as follows: 1) Nursing Care at the End of Life, 2) Pain Management, 3) Symptom Management, 4) Ethical/Legal Issues, 5) Cultural Considerations in EOL Care, 6) Communication, 7) Grief, Loss, Bereavement, 8) Preparation and Care for the Time of Death, and 9) Achieving Quality Care at the End of Life. This article presents strategies for teaching Module 6, Communication in End of Life Care.

Several common themes, or threads, are integrated throughout all the modules, as well as Module 6:
- The family as the unit of care.
- The important role of the nurse as advocate.
- The importance of culture as an influence at the end of life.
- The critical need for attention to special populations such as children, the elderly, the poor, and the uninsured.
- The impact of EOL issues on all systems of care across all settings.
- The influence of critical financial issues on EOL care.
- EOL care as an essential aspect in cases of sudden death and for all life-threatening illnesses.
- Interdisciplinary care as an essential component of quality care at the end of life.

Developing Competency in Communicating with the Seriously Ill

Module 6 reviews dimensions of communication, emphasizes the importance of good communication in EOL care, presents the complexities of communicating with patients and families, and offers certain communication techniques. Three key messages are reinforced:
- Communication is critical in all health care situations, but is of special significance at the end of life.
- Strong collaboration and communication between and among professionals is a prerequisite to communication with patients and families.
- Palliative nursing care requires skill in verbal and nonverbal communication, listening, and presence.

Four outcomes are expected from this module. Learners will:
- Define the importance of ongoing communication with the interdisciplinary team, patient, and family throughout an EOL process.
- Identify factors that influence communication in the palliative care setting.
- Describe important factors in communicating bad news.
- Identify characteristics that patients and families expect of the health care professionals who care for them.

Competent EOL and palliative nursing care begins with an understanding of communication techniques and their potential impact on care. Effective communication with the patient and family unit is crucial for successful outcomes, as terminal illness is a family experience. In a recent study, nurses were asked what they wish they had been taught in their nursing school curriculum regarding the terminally ill. The most common response was “how to talk to patients and families about dying” (1).

Communication involves conveying essential factual information to help dispel preconceived notions and myths about illness or treatment and allow individuals to make informed decisions related to care. Communication also involves strong collaboration among members of the interdisciplinary team. To develop an individualized plan of care that is based on the patient’s self-directed goals, needs, and overall con-
dition, the lines of communication among all disciplines, the patient, and the patient's family must be open.

Initiating any plan requires an understanding of the patient's and family's knowledge of the disease status and prognosis (2). Sidebar 1 contains a list of communication expectations as published in the ELNEC course syllabus. These must be understood by nurses before they can develop an interdisciplinary plan of care that enhances quality of life for the patient and family.

**Factors Affecting Communication** Difficulty in communicating may result from various factors, such as problems in the family system; financial, educational, and physical concerns and limitations; and the stage of coping and grief. With regard to the patient and family system, actual or perceived lack of continuity among caregivers can occur when information from the health care team is interpreted in different ways. For some families, for example, death may be a new experience, and previous coping skills may not be helpful. New coping skills may be required to respond to this unfamiliar situation.

Perceived or real lack of support among family members may contribute to feelings of distress and being overwhelmed (3). The inability to care for family members, either physically or emotionally, can lead to further distress for family caregivers who, without adequate support and care, may feel abandoned and isolated. Ultimately, the crisis of the impending death of a loved one can also affect the family members' ability to hear and understand information.

Financial, educational, and physical variables may also have an impact on the family's ability to communicate. Medical expenses, lost time from work, and other costs of caregiving can jeopardize financial security, leading to the loss — or the fear of loss — of treasured items, including one's home. Such situations provoke anxiety, stress, and grief in family members experiencing terminal illness.

One's educational level and ability to read can influence one's understanding of the potential impact of the illness and ability to make informed decisions about treatment. Too much medical information, rapidly changing and multiple care providers, complicated treatment protocols, and the use of medical jargon contribute to information overload.

Physical factors that affect communication may include sleep deprivation. Physical exhaustion will have a negative influence on the caregiver's ability to process information and provide the care required by the patient. For patients, medical interventions, disease processes, and co-morbid conditions can affect the ability to comprehend and communicate. Loss of the ability to speak and communicate one's wishes brought about by surgical interventions, such as tracheostomy, and the ability to process information resulting from the effects of medications must be addressed by the nurse and members of the palliative care team.

Stages of coping and grief, including anticipatory grieving regarding the loss of self or another, also affect communication. Anger about the present situation and its impact on the family are important issues that need to be addressed by the health care team. Fear of a future without a loved one and apprehension about life after death are existential concerns that require the interdisciplinary intervention of counselors, chaplains, and others. Possible areas for exploration may involve spiritual concerns related to regret about earlier life decisions or lifestyle choices, changes in family dynamics and roles during serious illness, and expectations about how death will further affect the individual's role in the family. Open communication is needed to resolve all these issues, and team members need to be prepared to help families as they work through their fears and concerns.

**Sidebar 2. Six-Step Protocol for Breaking Bad News**

1. Get the physical context right.
2. Find out how much the patient knows or suspects.
3. The factual content of the patient's statements.
4. The style of the patient's statements.
5. Emotional content of the patient's statements.
6. Find out how much the patient wants to know.
7. Share medical information.
8. Align (using patient's words and current knowledge).
9. Educate.
10. Give information in small amounts.
11. Use English (not medical jargon).
12. Check reception frequently.
13. (Check that message is being received.)
14. Reinforce the information frequently.
15. Blend concerns and anxieties with those of the patient.
16. Respond to the patient's feelings.
17. Plan and summarize.

- Identify coping strategies of the patient and reinforce them.
- Identify other sources of support for the patient.

Helping Patients and Families Cope  Past coping experiences predict how individuals will cope in new situations, but terminally ill patients are at risk for depression. Thus, the assessment of depressive symptoms should be continuous. In some cases, both the patient and family members may wish to “hide” prognosis information in an effort to protect the other. This “conspiracy of silence” should be addressed with the understanding that many cultural influences affect communication at the end of life. Team members should strongly encourage honesty among family members when discussing treatment and prognosis issues (4), but cultural influences need to be respected.

It is important for children to be told the truth regarding their own illness or the illness of a significant other at a level they can understand. Children should be allowed to visit sick loved ones if they choose, and their daily routines should be maintained as well as possible (5).

Family caregivers require extensive support for the emotional and physical stresses and burdens of caregiving. Many caregivers experience guilt because they are unable to halt the progression of the disease. Caregiver support groups can be helpful for coping with these feelings.

A feeling of helplessness as one loses independence or watches the decline of self or a family member is very distressing. As independence vanishes and physical functioning declines, patients will experience a loss of control. Nurses can provide opportunities for individuals to vent their concerns (6). Through communication, patients can be encouraged to explore ways of promoting independence and maintaining a sense of control.

Helping families maintain hope in the face of decline is an important nursing intervention. For many families, denial is an effective coping strategy that allows the individual and family to integrate the impact of the diagnosis and prognosis. Denial can help the individual “pull together” in preparation for active treatment or for a shift to palliative care.

Breaking bad news is a very difficult task for health care providers. Talking about death, in general, is a difficult task in our culture, and good communication is vital. While physicians generally present the initial news, nurses are constantly expected to reinforce information and provide clarification. A six-step protocol for breaking bad news (7) is found in Sidebar 2.

Teaching Strategies in the Classroom  In the ELNEC Training Program, recognition is given to the importance of communication skills at the end of life, specifically the communication of bad

Sidebar 3. Barriers to Good Communication at the End of Life

- Fear of one’s own mortality can influence the professional’s ability to address this subject.
- Lack of personal experience with death and dying can increase reluctance to discuss this topic.
- Fear of expressing emotion, such as showing tears, may cause some individuals to avoid difficult topics.
- Health care professionals are trained to be responsible for patient outcomes. Society often places unrealistic expectations for cure. Fear of being blamed for causing death is a real concern.
- Fear of not knowing the answer to a question or whether to be honest when answering a question are two significant barriers to open communication.
- Disagreement with patient/family decisions can negatively impact further communication with family members.
- Lack of knowledge/understanding of the patient’s/family’s culture may lead to poor communication.
- Lack of knowledge/understanding of the patient’s/family’s end-of-life goals, wishes, and/or needs may lead to inappropriate decisions that do not respect the values and goals of patients and families.
- Unresolved personal grief issues, such as the loss of one’s own parents, may interfere with the professional’s ability to be objective.
- Ethical concerns, which may lead to disagreements between patients, family members, or health care providers related to care, are difficult to discuss but should be addressed openly and, if necessary, with the assistance of an ethics consultation team or ethics committee.
- Professional insensitivity demonstrated by interrupting communication, patronizing, and not allowing patients/families to express their views, is inappropriate and should be confronted by other team members. It is very important to involve family members in communication about decisions related to treatment or withdrawal of treatment in the palliative care environment.
- Professionals who keep physical and/or emotional distance from patients, such as standing away from the patient or avoiding eye contact, create communication barriers before verbal interaction has begun. Professionals need to work on improving skills such as sitting at eye level and using good eye contact when communicating with patients and their families.

Note: From End of Life Nursing Education Consortium (ELNEC) Course Syllabus. Copyright 2000 by American Association of Colleges of Nursing and the City of Hope National Medical Center.
Sidebar 4. Questions to Ask Patients and Families to Elicit End-of-Life Goals

- Are these questions part of your assessment?
- What do you think is most important to your family?
- What are your needs at this time?
- What are your concerns at this time/for the future?
- What do you want to accomplish or do?
- What do you wish you could still do?
- What are the things that bring you joy/comfort?
- What is important for you to maintain control over?
- What do you feel you have control over...disease/pain/decisions?
- What do you know about your illness/disease? Is there anything else you would like to know?
- How do you feel about your treatments (medications, radiation, chemo, DNR)?
- If you have pain, what would be an acceptable pain level for you on a 0-10 scale?
- What activities, such as music, art, reading, massage, touch, provide peace or comfort to you?
- What are the most important relationships in your life?
- Is there anyone you would like to see/talk to/visit with?
- What are you proud of? What are your greatest achievements?
- How and where do you want to live for the rest of your life?
- Where (environment) are you most comfortable?
- What are you hopeful about?
- What spiritual or religious practices bring you comfort?
- Is spiritual peace important to you? What would help you achieve spiritual peace?

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This exercise involves discussion of a list of questions to elicit EOL goals (see Sidebar 4) that would be useful for guiding the interdisciplinary care plan. (See Sidebar 5 for a description of the Listening Exercise and the Exercise to Elicit End-of-Life Goals.)

Two 10-minute film clips from the HBO video “In the Gowning” are shown during the ELNEC training session. (See Sidebar 6 for information about this and other resources.) Participants are given several questions to think about as they watch the video. In the opening scene of the first clip, Danny, a young adult dying from AIDS, returns to his parents’ home after several years. In a scene depicting a family meal with Danny, his parents, and his adult sister, poor family dynamics and communication patterns are illustrated. The questions for this clip center on the family’s verbalized priorities and regrets.

In the second clip, Danny is in bed, close to death. Myrna, his private duty nurse, is at his bedside, and his mother, Janet, stands tentatively at the door. Myrna invites her in and lovingly coaches her in new ways to care for her son. The discussion questions for this scene involve the nonverbal communication between Myrna and Janet.

All the training modules involve the use of case studies and discussion questions featuring patients of all ages who are at the end of life. Questions included with the scenarios for Module 6 help the learner explore communication issues, deliver bad news, and consider the matter of interdisciplinary communication.

Learners bring a variety of personal and professional experiences to the training session that can be used to launch discussions about communication skills and form the basis for other case studies. The writer (learner) becomes the expert in the details of the case and the instructor creates discussion questions, or uses role-play, to teach the salient points.

Sometimes drama students act out the roles. This approach takes more time to script, but the scenarios may be used for several groups of learners. The TNEEL program on CD-ROM includes audio and video clips that are effective when used in the classroom. This resource adds an interactive dimension to the presentation of communication skills.

Strategies for Clinical Teaching The clinical setting is invaluable for teaching communication skills, as learners are able to experience communication in the everyday lives of patients, families, and clinicians. A hospice in-patient facility is an excellent clinical site. A suggested schedule follows.

The day begins with a conference to communicate the instructor’s expectations of the learners and vice versa. This is
FEAR OF A FUTURE without a loved one and APPREHENSION about life after death are existential concerns that REQUIRE THE INTERDISCIPLINARY INTERVENTION of counselors, chaplains, and others.

Sidebar 5. Sample Exercises

#1. LISTENING EXERCISE
This exercise is intended to give participants/students an opportunity in active listening. It provides both an experience in describing loss and in expressing emotions, as well as, most importantly, an opportunity to listen intently in silence.

Divide into groups of two. One of the two partners, the “speaker,” will take five minutes to describe a significant personal loss, such as the loss of a person, a pet, an object/home, or some aspect of health. The second partner, the “listener,” must listen silently and may not speak at all during the five-minute time period.

Questions for Guiding Discussion

For the “Speaker”:
• What did it feel like to describe your loss?
• How did the listener respond to you?
• Did you feel that the listener was being attentive?
• Was there any particular thing that made you feel the listener was, in fact, listening to you?

For the “Listener”:
• How did it feel for you to listen in silence for five minutes?
• Did the five minutes seem short or long?
• What aspects of the telling of the story of loss were most significant to you?
• What did you learn from this experience of attentive listening?

#2. EXERCISE TO ELICIT END-OF-LIFE GOALS (30 minutes)
This exercise is a way to have students focus on the importance of communication with patients and families. It helps define what is important to patients at this time in their lives and helps formulate goals that will guide the interdisciplinary care plan.

1. Create Triads of Nurse, Patient, Observer (8 minutes): Read “Questions to Elicit Goals” (Sidebar 4) and discuss which questions would be most helpful as the patient being asked and as the nurse asking the questions.

2. Role-Play (8 minutes): Ask participants to role-play this communication in their triads. Let them know there will be time at the end to discuss the quality and outcome of these communications.

Nurse: Create dialogue using “Questions to Elicit Goals” or similar questions to help a patient who is aware of his/her limited life expectancy identify what is personally important at this time.

Patient: You are a patient who is aware of your limited life expectancy and are beginning to consider what you want to happen during this limited time of your life. Engage in dialogue with the nurse.

Observer: Observe the verbal and nonverbal communication between the nurse and the patient. Be ready to describe the quality and outcome of the dialogue.

3. Group Discussion (10 minutes): Facilitate discussion to address the quality and intensity of this dialogue. Point out how initiating dialogue can assist patients and families to identify what is important to them and how, as professional caregivers, we can direct our care based on what they have communicated.

Questions for Facilitating Group Discussion.
Patient: What did it feel like to answer these questions? Did they help you to focus on or communicate your priorities?

Observer: Discuss the quality of the communication, including the verbal and nonverbal communication, between the nurse and the patient.

Nurse: What did it feel like for you to have this dialogue?

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Sidebar 6. Resources

CD-ROM RESOURCES


Three-CD set of instructional material sponsored by the University of Texas M.D. Anderson Cancer Center. Covers wide range of topics including basic principles, first-line diagnosis and treatment, disease progression, genetic counseling, aspects of oncology nursing, patients and families.

BROCHURES

Communicating Your End-of-Life Wishes. This brochure emphasizes the importance of communicating end-of-life wishes to family and loved ones and how to take advantage of significant life events. Contact National Hospice Foundation, 1700 Diagonal Road, Suite 625, Alexandria, VA 22314; 703/516-4928, fax 703/837-1233, www.hospiceinfo.org, e-mail nhf@nhpc.org.

TOOLS

ToolKit for Nursing Excellence at End of Life Transition. TNEEL is a package of electronic tools for palliative care education. Contact Dr. Diana Wilkie, University of Washington, Seattle, WA, http://www.son.washington.edu/department/bnhs/pain/tneel.asp.


VIDEOS


Making Choices (15 minutes). Featuring poignant conversations with individuals dealing with difficult end-of-life decisions, “Choices” focuses on the values and issues that guide decision-making and the importance of advance directives. Accompanied by a value history questionnaire that can be used to help viewers explore their own values. The video and questionnaire together provide an excellent basis for a community education program.

Choice in Dying Publications/Videos, V100

Gundersen Lutheran Medical Foundation, 800/362-9567, x6748.

Life Support Decisions (50 minutes). This important video will help elders, their families, and professionals understand rights and options regarding life-support technologies and end-of-life care and decision-making. Its discussion of issues involved in preparing Advance Directives encourages communication.


a time for discussing the learners’ fears and other barriers to care. The learners are then paired with a hospice nurse, and the instructor rotates throughout the faculty talking with patients, families, and staff.

The learners have four objectives for this clinical experience: 1) Ask the patient to tell his or her story and be present to the person by listening intently. 2) Elicit the patient’s most important concern for the day. 3) Ask the patient’s opinion about what nurses need to know about caring for people at the end of life. The most common response to this question is “be there to listen to the patient.” 4) Attend an interdisciplinary team meeting.

Many learners comment about the communication skills observed during a hospice interdisciplinary team meeting. They report being struck by the variety of perspectives of the same clinical situation voiced by the different members of the team. The learners are encouraged to express their own viewpoints and consider the values and beliefs that influence their views and opinions.

Role-modeling in the clinical setting is extremely valuable. The instructor and staff explore patient and family goals with the learner at the bedside. The day ends with a postconference to discuss lessons learned throughout the day.

The Benefits of Positive Communication Participants at the ENLCE conferences have recognized, through experiential exercises, the importance of listening and being listened to. Speakers share their fears, concerns, and suffering, as well as their hopes and dreams, in the hope that they will be taken seriously. Nonverbal feedback by the listener — maintaining eye contact, shaking one’s head in understanding, extending one’s hand in support, leaning forward — provides signs of acceptance,
worth, and personal regard and encourages open, empathic discussion of difficult issues. Listeners in the exercises recognize the energy and commitment needed to remain focused and attentive to what is being said. They learn to avoid engaging in "self-talk" while planning a response.

Through these experiences, ELNEC participants identify receptivity and a nonjudgmental attitude as essential to the development of a trusting nurse-patient relationship, a relationship in which care goals are discussed and strategies planned within the context of the patient’s and family’s preferences and the best judgments of the health care team. By watching videotapes and role-playing, participants develop a heightened awareness of verbal and nonverbal messages, and questions that beg to be asked.

The ways that nurses communicate their willingness to bear witness to suffering and offer their presence are often perceived by patients and families as the most important of all interventions. Taking the time to listen actively and process not only words and facts, but also meanings and feelings, is the quintessential task of communication at the end of life. By highlighting barriers and facilitators to therapeutic communication, the ELNEC module on communication teaches how to communicate bad news and respond with empathy.

The program further recognizes that communication is important for strengthening the interdisciplinary team and developing an appreciation for the strengths and contributions of each member of the team. Respectful, trusting, and collaborative discussions among all team members, along with the patient and family, are central to all decision-making at the end of life.

Educators in all settings are encouraged to attend an ELNEC training course to learn more about all nine of the end-of-life nursing education topics. The ELNEC website will also help educators identify others who have experienced ELNEC training for possible collaboration in planning educational activities.

**Key Words** Faculty Development – Interdisciplinary Team – Nursing Education – Hospice – Communication – Palliative Care – End-of-Life Care

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