Palliative Care NURSING EDUCATION: OPPORTUNITIES FOR GERONTOLOGICAL NURSES
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ABSTRACT
Approximately 80% of Americans who die each year are 65 or older. Increasingly, gerontological nurses are asked to deliver high quality end-of-life care. Studies, however, have identified deficiencies in the delivery of care to older adults who are dying—particularly those who die in nursing homes. Enhancing nursing education and training in end-of-life care is one strategy proposed as a remedy for inadequate care for nursing home residents who are dying. This article reviews the current status of end-of-life nursing home care, describes the philosophy and components of quality palliative care, and provides information about opportunities and resources for educating gerontological nurses in end-of-life care.

Two and a half million individuals die each year in the United States. Approximately 80% of those who die are 65 or older (Last Acts, 2002). Increasingly, Americans are dying in nursing homes. By 2040, an estimated 40% of individuals will die in this clinical setting (Brock & Foley, 1998; Teno, Bird, & Mor, 2001). These statistics indicate that gerontological nurses will provide much of the end-of-life (EOL) care in the United States.

Despite the prominence of their role, gerontological nurses, especially those working in nursing homes, are often ill-prepared to deliver this care. In one study, families described nursing homes as unable to provide specialized, palliative care at the EOL, an inadequacy that negatively affected their relatives’ quality of life (Maccabee, 1994). Hanson, Danis, and Garrett (1997) reported that families expressed distress over staff being poorly trained in palliative care, which may have contributed to increased suffering for their loved ones. Gibbs (1995) reported that nurses practicing in nursing homes were less likely to have had continuing education courses

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WORLD HEALTH ORGANIZATION DESCRIPTION OF PALLIATIVE CARE

Palliative care:
- Provides relief from pain and other distressing symptoms.
- Affirms life and regards dying as a part of the life cycle.
- Intends neither to hasten nor postpone death.
- Offers a support system to help patients live as actively as possible until death.
- Offers a support system to help the family cope during the patient’s illness and in their own bereavement, including the needs of children.
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated.
- Will enhance the quality of life, and may also positively influence the course of a patient’s illness.

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about pain management and palliative care than nurses in acute care settings. In addition, nurses in nursing homes were less able to identify treatment options for patients in pain.

Several studies have shown the importance of making enhanced palliative care education available for health care providers in all clinical settings (Ferrell, Grant, & Virani, 1999; Field & Cassel, 1997; Last Acts, 2002). Trends in EOL care and documented deficiencies in the care of older adults with life-threatening illness underscore a growing urgency to ensure gerontological nurses are well prepared to provide palliative care.

HOSPICE AND PALLIATIVE CARE

The modern hospice movement in the United States began during the 1970s as a grassroots effort aimed at providing humane EOL care. In part, it reflected the growing dissatisfaction with disease-driven health care and the extensive use of high-tech interventions for dying patients (Egan & Labyak, 2001; Volker & Watson, 2002). Hospice expanded from a philosophy of care to a program of care in 1983 with the establishment of the Medicare Hospice Benefit (MHB), which funds much of the hospice care provided in the United States. The MHB also established regulatory requirements for hospice programs. Later amendments to the MHB allowed nursing homes to be designated as a hospice patient’s home and paved the way for hospice care delivery in long-term care facilities (Ersek & Wilson, 2003). Medicaid and private insurers also offer hospice services, and many of their programs are patterned after the MHB.

Hospice has influenced greatly the way Americans die. However, since the inception of the MHB, the shortcomings of this funding have been documented. The MHB provides the easiest access to hospice care among patients with advanced cancer and a 6-month prognosis, those living at home with an established family caregiver network, and those who choose to have no further life-sustaining medical therapy (Egan & Labyak, 2001; Kinzbrunner, 1998). The prognostication of a 6-month-or-less survival prevents many dying patients with non-cancer diagnoses from receiving hospice care, including those with cardiovascular disease, lung disease, and dementia.

Patients, or their surrogate decision-makers, must sign an informed consent for hospice services. Often, they are reluctant or unwilling to forego life-sustaining therapies. Determining which therapies are palliative and which are inappropriate at EOL is difficult, even for experienced clinicians (Volker & Watson, 2002). Another challenge for hospice funding is the high percentage of deaths that still occur in acute care settings (Volker & Watson, 2002).

The limitations of hospice care have spurred the development of different ways to provide EOL care. Palliative care, which has emerged in the past two decades as a philosophy of care and a clinical specialty, is one strategy to move hospice care “upstream” and provide holistic supportive care earlier in the disease process. The World Health Organization (WHO) (2002) describes palliative care as:

an approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention, assessment and treatment of pain and other physical, psychosocial and spiritual problems.

The WHO also delineates the philosophical and service components of palliative care, underscoring the importance of care that allows patients to live as fully as possible until their deaths (Sidebar). The National Consensus Project for Quality Palliative Care (2004) has expanded on the WHO definitions by developing Clinical Practice Guidelines, which provide core concepts and structures for palliative care programs.

The philosophy and components of palliative care are very similar to those for hospice (Volker & Watson, 2002). Palliative care, however, is not limited by MHB restrictions and serves patients earlier in the course of a life-threatening disease. Because there are no requirements for a specific life expectancy, clinicians can more easily provide services to patients with non-cancer diseases. Because palliative and curative therapy can occur concurrently, patients and families may be more willing to accept palliative care than hospice services.

Although the relationship between traditional hospice and palliative care is evolving, the Figure shows one commonly used depiction of the association among key EOL services. In the future, the respective roles of palliative care programs and traditional hospice services will be determined by the reimbursement mechanisms for each service. If hospice continues to be funded via the existing MHB, its role will be
focused on the final weeks and months of life. Newer reimbursement strategies ideally will provide for care focused on symptom palliation beginning at the time of diagnosis of a life-threatening disease and continuing until death.

These recent trends in palliative care enable patients and their families to receive expanded EOL services in a variety of settings (National Consensus Project for Quality Palliative Care, 2004). These changes also challenge clinicians in non-hospice environments to acquire additional skills and knowledge of palliative care. This need to enhance staff expertise also applies to nursing homes, where fewer than 1% of residents receive hospice care at any given time (Petriske & Mor, 1999).

Although some authors recommend increased hospice utilization, alternative models have been proposed to achieve high-quality, comprehensive palliative care in nursing homes and other settings that serve older adults (Ersek & Wilson, 2003). Other models of comprehensive palliative care for frail older adults include the Programs of All-Inclusive Care for the Elderly (PACE) (Rollins, 1999), Palliative Excellence in Alzheimer’s Care Efforts (PEACE) programs (Shega et al., 2003), and nursing home palliative care teams and consulting services (Ersek & Wilson, 2003). Regardless of the specific delivery system, gerontological nurses with little or no palliative care training increasingly are expected to manage complex EOL symptoms and to direct or provide holistic EOL care.

EDUCATIONAL OPPORTUNITIES
End-of-Life Nursing Education Consortium

In their seminal report on EOL care, the Institute of Medicine called for (Field & Cassell, 1997):

...changes in undergraduate, graduate and continuing education to ensure that practitioners have the relevant attitudes, knowledge and skills to care well for the dying patient. (pp. 268-269)

As a result of their recommendation, Ferrell et al. (1999) initiated an ambitious plan to enhance EOL nursing education. One element of the project was the development of a comprehensive curriculum called the End-of-life Nursing Education Consortium (ELNEC).

Funded by the Robert Wood Johnson Foundation in 2000, ELNEC addressed deficiencies in nursing education related to EOL care (Ferrell et al., 1999; Matzo, Sherman, Penn, & Ferrell, 2003). The program goal was to assist nurse educators and clinicians to meet the American Association of Colleges of Nursing (AACN) recommendations articulated in the document entitled Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Nursing Care (2002). A team of consultants developed the curriculum with leadership from the City of Hope National Medical Center and the AACN.

Organized into nine modules, the ELNEC curriculum is delivered in a 3-day “train-the-trainer” course. The modules cover the major areas of EOL care, such as:

- Cultural issues.
- Communication skills.
- Grief and bereavement.
- Pain and symptom management.

Each module begins with a 45- to 60-minute didactic presentation reviewing essential content using a Microsoft® (Redmond, WA) PowerPoint® slide show. Some modules also include poetry, literature, or video clips. The second half of each module covers teaching strategies focusing on experiential learning. Using this course structure, the ELNEC curriculum encompasses the major domains of nursing education and care: cognitive, affective, and psychomotor (Matzo, Sherman, Penn, et al., 2003). Detailed content and teaching strategies also are described in several articles (Matzo et al., 2002; Matzo, Sherman, Lo, et al., 2003; Matzo, Sherman, Sheehan, Ferrell, & Penn, 2003; Sherman, Matzo, Panke, Grant, & Rhome, 2003; Sherman, Matzo, Rogers, McLaughlin, & Virani, 2002).

One faculty member from each participating facility (e.g., school of nursing, hospital) attends the appropriate ELNEC program and is expected to use the training to teach students, nursing staff, and other faculty about EOL care. ELNEC was originally designed for baccalaureate and associate degree nursing faculty, continuing education providers and staff development educators, and nurses in regulatory agencies such as state boards of nursing who exercise influence over nursing care standards. With continued funding from the Robert Wood Johnson Foundation and the National Cancer Institute, the curriculum has since been adapted for pediatric nurses, oncology nurses, and graduate nursing programs.

Palliative Care Educational Resource Team

Another educational curriculum, the Palliative Care Educational Resource Team (PERT) program, was developed and tested with funding from the National Cancer Institute (R25CA82563). The goal of the program is to enhance EOL care in nursing homes through the education of nursing assistants and licensed nursing staff. The curriculum consists of four day-long classes and...
covers all major areas of EOL nursing care (Table). Parts of the curriculum (e.g., symptom management, establishing the goals of care) have two components—one specifically designed for licensed staff and another specific to nursing assistants. Other sections, such as the communications workshop, are attended by licensed staff and nursing assistants together. Interaction among staff from different facilities is encouraged as a way to build a sense of community among caregivers and to share successful strategies for providing EOL care. In fact, 108 licensed staff members and 62 nursing assistants from 45 facilities completed the PERT course, and program evaluation demonstrated that significant increases in knowledge and clinical skills were achieved (Ersek, Grant, & Kraybill, 2005).

The PERT program incorporates content and learning experiences specific to gerontology nurses and long-term care. For example, the section on “Establishing the Goals of Care” includes an extensive discussion about decision-making and residents with dementia. Participants discuss the myriad resident and family decisions that direct care at EOL in review types of advance directives. They explore biases about the decision-making capabilities of frail older adults, especially cognitively impaired residents. Faculty present research documenting that many residents with dementia are able to express their wishes reliably (Mezey, Teresi, Ramsey, Mitty, & Bobrowitz, 2000). Participants learn about the ethical standards and concepts guiding surrogate decision-making and review the laws dictating who is authorized to make decisions when the resident is unable and does not have a designated health care proxy.

Pain and symptom management classes for both licensed staff and nursing assistants emphasize the special considerations for assessing and managing symptoms in cognitively impaired residents. Participants are challenged to examine their own assumptions about the reliability of self-reports of pain and other symptoms among residents who are cognitively impaired. Similar to the “Establishing Goals of Care” content, faculty review research showing that many older adults who are cognitively impaired, even those with moderate to severe dementia, are able to provide valid and reliable reports of pain (Feldt, Ryden, & Miles, 1998; Ferrell, Ferrell, & Rivera, 1995). Assessment and management of pain in residents who are severely impaired and nonverbal is covered in detail.

The self-care and communication workshops include discussion about the stresses encountered by nursing home staff who often see themselves (and are seen by residents) as “family.” Many residents live in a facility for many years and staff come to know residents’ habits, likes and dislikes, and fears and joys as well as or better than family members. When these residents die, staff can experience a profound sense of loss. The PERT program includes opportunities to explore the rewards and challenges of caring for dying residents and ways to cope with cumulative losses.

In addition to the classes, PERT participants receive a syllabus containing class notes, copies of slides, case studies, additional readings and handouts, bibliographies, and inspirational quotations and literature. Participating staff and facilities also are encouraged to access the PERT program Website, which provides course materials and links to other relevant Websites. Additional Website resources include an extensive EOL bibliography, a Tip of the Month section containing brief informational articles on a variety of topics, and a PERT advisor section in which program faculty answer questions submitted by participants.

In 2004, the PERT program was adapted for delivery to nursing staff development educators. Content was updated and packaged in a “train-the-trainer” format to increase access to the program. Participants attended a 2-day training course, which covered both content and teaching tips, and received a syllabus and a CD-ROM containing all course materials. Eighty-seven participants attended the Train-the-Trainer workshops. They reported significant increases in their confidence and skill in teaching EOL content. As a result of the workshop, participants conducted more than 100 in-services, which reached more than 2,000 nursing home staff members (Ersek, Kraybill, & Hansen, 2005).

Toolkit for Nurturing Excellence at End-of-Life Transition

The Toolkit for Nurturing Excellence at End-of-Life Transition (TNEEL) program is a computerized, multimedia tool designed to assist academic and clinical nurse educators in teaching palliative care con-
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<tr>
<th>Component</th>
<th>Specific Topics</th>
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<tbody>
<tr>
<td>History and philosophy of hospice and palliative care</td>
<td>Trends in dying—Chronic illness as cause of death, increase in technology at end of life; changing views on dying and death; concept of “a good death”; hospice movement, current hospice practice; definition and delivery of palliative care; interdisciplinary team</td>
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<tr>
<td>Pain management</td>
<td>Prevalence, definitions, causes, and types of pain; effect of pain on quality of life; barriers to effective pain management; assessment, pharmacological management; non-drug therapies</td>
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<tr>
<td>Symptom management</td>
<td>Assessment and pharmacologic and non-drug management of common end-of-life symptoms (e.g., dyspnea, constipation, nausea and vomiting, anorexia/cachexia, dysphagia, anxiety, depression, delirium, urinary and bowel incontinence, edema ascites)</td>
</tr>
<tr>
<td>Decision-making</td>
<td>Importance of discussing and documenting patient and family goals; identifying and discussing values; advance directives—types, history, forms, limitations; how to discuss treatment goals; determining capacity and decision-making ability; cultural variations in decision-making</td>
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<td>Communication</td>
<td>Basic communication skills, delivering “bad news,” conducting a patient and family care conference, managing conflict, identifying team roles and team building, educating patients and families about the dying process, how patients communicate at the end-of-life</td>
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<td>Cultural issues</td>
<td>Changing demographics; definitions; cultural influences on communication, attitudes towards death and health care, decision-making, communication, expressions of grief; bereavement; cultural assessment</td>
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<td>Loss, grief, and bereavement</td>
<td>Definitions; grief as a normal process; phases of grief; examining personal views on death and grief; assessing grief; intervening for grieving patients, families, and staff; coping with cumulative losses</td>
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<td>Spiritual care</td>
<td>Definitions of spirituality and religion, importance of spirituality at the end-of-life, religious and spiritual perspectives on dying and after-death, religious bereavement rituals and beliefs, assessing spiritual needs at end-of-life, identifying spiritual distress, spiritual interventions, helping patients and families maintain hope</td>
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<td>Ethical and legal issues</td>
<td>Definitions of ethics, morality, and ethical dilemma; ethical principles—definitions and application to end-of-life care; common ethical dilemmas that arise in end-of-life care (e.g., administering opioids, decision-making, medical futility, assisted death, truth-telling); ethical decision-making process, applying ethical decision-making to end-of-life dilemmas</td>
</tr>
<tr>
<td>Care when death is imminent</td>
<td>Indicators of imminent death, family teaching and support, assessing for and intervening for symptoms in the last hours of life, signs that death has occurred, caring for the body after death, nursing tasks immediately following patient death</td>
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<tr>
<td>Caregiver self-care</td>
<td>Sources of caregiver stress, manifestations of stress, strategies to cope with stress of caring for the dying and their families</td>
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<tr>
<td>Economic issues</td>
<td>Reimbursement for care, changing health care systems, understanding economic issues and outcomes, access to care, Medicare hospice benefit, quality of care, quality improvement</td>
</tr>
<tr>
<td>Professional issues</td>
<td>Trends in hospice and palliative care, nursing roles, standards of care, certification, public policy and advocacy, continuing education</td>
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Ethics (legal and ethical decision-making at EOL).  
Well-being (hope, suffering, complementary therapies, and spiritual and psychosocial needs).  
Grief (grief, loss, and bereavement).  
Impact (effect of EOL care on patients, families, and society).  

The teaching materials, available on CD-ROM, include a lecture outline, more than 1,000 PowerPoint® slides, speaker notes, and audio and video clips. Other resources are student learning objectives, case studies, attitude and knowledge assessment questions, and informational resources, such as equianalgesic charts and symptom assessment scales. All materials are integrated into an easily navigable...
computer program. Although the program is not targeted for gerontology clinicians, there is some dedicated geriatric content.

Although this program can be used without training, the TNEEL investigators conducted several 7-hour, hands-on training workshops. These workshops oriented users to the program’s content and resources, and included several interactive assignments to help attendees practice using and problem-solve any difficulties with the technological elements of the toolkit. The goal of the workshops was to ensure that educators with little palliative care or computer background could use the program easily. An evaluation of the workshop and the toolkit demonstrated high acceptance and satisfaction (Willie et al., 2004).

Initially funded by a grant from the Robert Wood Foundation, free copies of the TNEEL CD-ROM were distributed to faculty in all baccalaureate and associate degree programs and to many clinical settings. Currently, TNEEL is available for the cost of shipping and handling (www.tneel. uic.edu). An online, self-study version (TNEEL-SS) also has been developed.

Hospice and Palliative Nurses Association

Another source for educational offerings is the Hospice and Palliative Nurses Association (HPNA). HPNA publishes hospice and palliative nursing Standards of Practice for all levels of nursing and core curricula for generalist RNs, advanced practice nurses (APNs), licensed practical nurses (LVNs/LPNs), and nursing assistants. The association includes nurses who provide hospice and palliative care in any care setting, including long-term care. They also have a Geriatrics Special Interest Group. HPNA publications and educational offerings regularly focus on topics specific to caring for older adults.

Among its many activities, HPNA publishes a peer-reviewed journal; sponsors national conferences; oversees a speaker’s bureau; and offers monthly teleconferences for APNs, RNs, LPN/LVNs, and nursing assistants. Members can join on-line forums to discuss and share information on specific clinical issues. HPNA also publishes position statements to guide nurses, facilities, patients and families, and policy makers on issues in palliative care. The position statements are published in their official publication, Journal of Hospice and Palliative Nursing, and on the HPNA Website. Two recent position statements that have particular importance for gerontological nurses and nursing home staff are “Artificial Nutrition and Hydration in End-of-Life Care” and “The Value of the Nursing Assistant in End-of-Life Care.”

In 2004, HPNA received a grant from the Project on Death in America to adapt and deliver the ELNEC curriculum to long-term care nurses. This program will be delivered three times annually for 3 years in different geographic areas. The HPNA course involves local chapter members who attend the ELNEC classes and bring a “buddy” from long-term care. Following the program, participants are invited to participate in the “Community of Practice,” which is a business model of networking individuals using the Internet. This virtual community comprises the attendees from the educational sessions and offers opportunities for exchanging valuable educational and clinical expertise within this defined group using an on-line dedicated site.

HPNA’s sister organization, the National Board for Certification of Hospice and Palliative Nurses (NB-CHPN®), oversees the certification process to advance quality in EOL nursing care. Certification is available for RNs, APNs, LPN/LVNs, and nursing assistants. Some of the educational materials that assist nurses and nursing assistants to prepare for their respective certification examinations are available through HPNA.

These three educational resources, ELNEC, PERT, and HPNA, continue to offer updated curricula and other learning opportunities. Further information is found at the following Websites:
- ELNEC: www.aacn.nche.edu/el nec/
- PERT: www.swedishmedical. org/PERT.htm
- HPNA: www.hpna.org
- TNEEL: www.tneel.uic.edu/

CLINICAL IMPLICATIONS
AND SUMMARY

The evolution and growth of hospice and palliative care services will continue. Several trends, including the aging of the American population, the preponderance of older decedents, and the increased number of deaths occurring in nursing homes, indicate the need for gerontological nurses to enhance their expertise in palliative care. Teaching and providing palliative care may be challenging for gerontological nurses who have not worked extensively with dying patients and their families. During the past several years, educational programs and resources have been developed to assist non-hospice and palliative care clinicians to acquire expertise in this area. This article described four EOL educational resources available to gerontological nurses and educators.

REFERENCES


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