Feature Article

Translating Knowledge Into Clinical Practice

A Unique End-of-Life Nursing Education Consortium Teleconferencing Program

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For learning to influence change in palliative clinical practice, education needs to be ongoing, incorporating specific interventions targeted to the learner, in a format that enhances knowledge and networking. This novel, online, interactive, case-based educational offering provided a method to allow ongoing integration of palliative care principles for health care professionals who attended the End-of-Life Nursing Education Consortium/Open Medical Institute courses in Salzburg during 2019-2022. Eight monthly teleconferences based on challenging clinical cases allowed discussion between palliative care professionals from 9 countries, serving as a mechanism for deepening theoretical information, allowing incorporation of best practice into the clinical setting, and, ultimately, improving care for all with serious illness. Many of the challenges encountered providing palliative care are universal. Through case vignettes, the group has been able to offer specific interventions, advances in practice, and discussions of approaches toward family and other health care professionals to provide optimal care. The participants report that the opportunity to learn from and support peers in other countries has been a rewarding and emotionally uplifting experience. These discussions were highly rated by participants who strongly voiced that the interactions would change their clinical practice to positively impact patient care.

KEY WORDS
End-of-Life Nursing Education Consortium (ELNEC), palliative care, teleconference

As palliative care services expand throughout low-resourced areas of the world, innovative educational models are needed to improve the knowledge and skills of health care professionals in these regions.[1,2] Several established educational programs from across the globe joined to develop and implement a novel, case-based teleconference to reach professionals throughout Central Eastern European countries. This collaboration began with the End-of-Life Nursing Education Consortium (ELNEC), which provides training for professionals in the field of palliative care.[3] Although originally conceived in 2000 to educate nurses in the United States, the ELNEC curricula have been translated into 12 additional languages, and courses have been held on 6 of 7 continents, representing 101 countries. At the current time, nearly 1.5 million professionals have been educated in ELNEC, nationally and internationally.[4-10]

The Open Medical Institute (OMI), an international initiative for health care professionals from transitioning countries to improve global health, sponsors 1-week intensive courses, which take place in Salzburg, Austria.[11] The ELNEC curriculum was first presented at an OMI seminar in Salzburg in 2006 and has been delivered 10 times,

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providing education to nurses, physicians, psychologists, physical therapists, and others interested in improving palliative care in their country. Fourteen countries across Central Eastern Europe/Central Asia (CEE/CA) have been represented, including Albania, Armenia, Czech Republic, Georgia, Greece, Hungary, Kazakhstan, Kyrgyzstan, Moldova, Poland, Romania, Russia, Serbia, Tajikistan, and Ukraine. The most recent course in 2022 included participants from Greece. Although technically not a Central Eastern European country, Greece faces similar challenges in the development of palliative care, and professionals were included in these Salzburg training seminars. These train-the-trainer courses are designed to improve care for those with serious illness by building the educational, leadership, and advocacy potential of the attendees.

The need for palliative care education in these regions is particularly acute.[12-17] It is estimated that, by 2060, 48 million people will die each year with serious illness, and 83% of these deaths will occur in low- or middle-income countries, which includes the CEE/CA region. These deaths will be associated with unnecessary suffering unless there is an expansion of palliative care services.[18] Unfortunately, barriers to palliative care currently exist in the CEE/CA region, including inadequate access to opioids and other essential medications, incomplete infrastructure and funding for care services, insufficient numbers of palliative care programs or specialists, and a lack of education of professionals and the public regarding palliative care.[19-29]

After the fall of communism, palliative care services slowly began to be developed throughout Central Eastern Europe. In Romania, the birth of palliative care is considered to be the moment when the Hospice Casa Speranței Foundation (HCS) was established as a charitable organization with the mission to introduce and develop palliative care throughout the country.[12] Starting as a palliative home care service for adults with advanced stages of cancer, HCS is now the largest Romanian nongovernmental organization providing medical service, with more than 250 full-time employees working in clinical services in Brasov County and in Bucharest. After 30 years of caring for more than 45 000 patients, HCS is now a regional leader and a center of excellence, offering national and international educational programs for more than 32 000 professionals working in palliative care, as well as advocacy and research.[14,30] Because of the success of this program as a training center of excellence, it was selected to house this new educational program of teleconferencing. Furthermore, one of the leaders (N.M.) at HCS attended the Salzburg ELNEC conference in 2010 and later became an ELNEC faculty member. Since 2019, she has also been responsible for recruiting, organizing, and coordinating the palliative nurse and other health care professional participants from CEE/CA who attend the ELNEC seminars in Salzburg.

Although the Salzburg ELNEC courses are highly rated, participants have identified a need for ongoing support and education. Using learning networks, such as Project ECHO as a model, leaders at Hospice Casa Speranței established a network of health care professionals within CEE/CA, including Albania, Armenia, Greece, Georgia, Hungary, Moldova, Kyrgyzstan, Kazakhstan, and Romania.[31,32] Supported by palliative care nurse educators within the United States, this consortium aims to improve palliative care delivery across the region through online, interactive, case-based discussions of challenging patient examples among an international working group of health care professionals.

METHODS

Leaders within this international consortium considered various learning opportunities to provide ongoing education regarding palliative care. They determined that the most feasible and cost-effective approach to engage health care professionals from numerous countries would be online, case-based presentations of challenging clinical experiences with robust discussion to allow all participants to contribute. Nursing and pharmacy professionals from the University of Rhode Island, who had a long-standing relationship with leaders from Hospice Casa Speranței, supported these conferences by sharing their experiences along with providing relevant resource materials.[33]

Participants

Health care professionals who had attended 1 or more of the previous 4 ELNEC seminars organized by the OMI from 2019 to 2022 were invited to participate. There were a total of 126 professionals who attended these Salzburg seminars during this time period, representing nurses, physicians, physical therapists, and patient advocates. These professionals came from 12 countries, including Albania, Armenia, Bulgaria, Georgia, Greece, Hungary, Kazakhstan, Kosovo, Kyrgyzstan, Moldova, Romania, and Ukraine. All of these individuals were invited to contribute to and attend the monthly teleconference.

Educational Intervention

The planning committee determined that a 1-hour, case-based monthly teleconference would provide an effective learning experience.[34,35] The time was set to accommodate European and US participants. The cases were selected by those who expressed willingness to present, were drawn from their clinical practice, and were based on experiences that were challenging or complex or led to moral distress. Examples included complicated caring needs (eg, fungating tumors, multiple stomas, extreme body image changes in patients) and ethical dilemmas regarding withholding or withdrawing treatment or care not consistent with patients' goals (eg, unnecessary blood tests, futile transfusions, parenteral hydration).

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A framework for the case vignette was provided by the teleconference organizers to provide structure to the presentations, including (1) general information on the patients' demographic data (gender, age, marital status, profession), diagnosis, co-morbidities, short medical history; (2) holistic evaluation of the physical, psychological, social, and spiritual issues identified; (3) plan of care including medications and nondrug therapies; and (4) particular details describing the challenges in the case, as well as any ethical or moral dilemmas encountered by the palliative care team.

An announcement e-mail was sent 2 weeks prior to the teleconference date providing the above details, naming the presenting country and the facilitator of the discussions. A friendly reminder e-mail was sent 1 week prior to the teleconference time, including an attachment of the proposed case for discussion. The platform used for the online connection was Zoom initiated by HCS. In both e-mail messages sent to participants, the Zoom link was provided, and a calendar invitation was included with the link.

RESULTS

Eight monthly teleconferences were conducted during 2022 (months during holidays or typical vacation times did not have a planned teleconference). Attendance ranged from 29 to 51 health care professionals, representing 10 countries. Representatives from 4 countries (Albania, Greece, Moldova, Romania) presented cases; 2 countries presented several times (Albania, Romania). All of the cases presented involved patients with advanced cancer, ranging in age from 24 to 78 years. Symptoms discussed during these presentations included pain, dyspnea, fatigue, insomnia, constipation, urinary dysfunction, nausea and vomiting, anorexia, dermatologic issues, lymphedema, depression, and anxiety (Table). There was robust sharing of information that might improve care, along with support for participants who expressed frustration, distress, and strong emotions while recounting these and other clinical cases. Despite the diversity of cultures and languages, complicated at times by the online format and network connectivity challenges, these participants formed a strong, cohesive group that provided encouragement and comfort to one another.

An online survey was conducted at the end of the 8 sessions to evaluate the effectiveness of this learning opportunity. Twenty-seven participants responded, including 25 nurses, 1 pharmacist, and 1 psychologist. When asked to rate the quality of the teleconferences using a 0-point (not effective) to 10-point (excellent) scale, the mean response was 9.2 (range, 7-10). Similarly, 96.3% of respondents affirmed that the teleconferences would have a positive impact on their patient care.

During the 1-hour teleconferencing time, the authors of this article kept individual written notes regarding the main themes that evolved during the discussion. Using thematic analysis, themes were independently identified and coded by 2 of the authors (N.M. and H.A.M.). These individuals then collaborated to determine that there was a high interrater reliability of these themes. The themes that evolved from the analysis of the 8 cases included ethical dilemmas, conflict regarding clinical care, and moral distress experienced by the palliative care team.

Ethical Dilemmas

Numerous ethical dilemmas were raised during these teleconferences, including withholding or withdrawing treatment at the end of life, particularly the challenges faced when assisting the patient and family/caregivers to recognize when to stop treatment and accept when the clinical status is irreversible. In addition, the palliative care team had to help overcome cultural expectations by family and caregivers that the function of the team was to "do" something, particularly performing interventions such as blood draw, hydration, or other tasks. Family members at times rejected the role of the team as a supportive, therapeutic presence, asking, "Why are you here?" if not providing treatment. The perception of the participants was that the focus on procedures, such as diagnostics or intravenous hydration, in the final days of life deflected from supportive interventions and end-of-life discussions.

Communication issues also presented ethical dilemmas. In these countries, individual autonomy is not highly promoted, valued, or understood. For this reason, oftentimes families attempt to take control of the loved one's situation, rather than focusing on the patient's goals and wishes. Patient and family unwillingness to openly discuss diagnosis and prognosis is another aspect of communication that leads to ethical concerns. This lack of communication regarding mortality frequently places the palliative care nurse in the middle of challenging interactions, whereby the patient asks the nurse not to tell the loved ones about the cancer, and at the same time, the caregivers ask the nurse not to tell the patients about their diagnosis. Furthermore, a paternalistic approach by physicians is frequently encountered, whereby the physician makes decisions on behalf of the patient, without investigating or considering the patient's desire.

Conflict Regarding Clinical Care

Participants noted the disconnect between international guidelines and current practice in their countries.[36,37] For example, several international guidelines recommend against the widespread use of tramadol and codeine for the treatment of severe cancer pain management.[38,39] Unfortunately, these agents are currently the drugs of choice in many Central Eastern European/Central Asian countries.[40] Three of the cases included discussion about tramadol and codeine's lack of efficacy due to genetic polymorphisms prevalent in these countries and concern about CYP 2D6 drug interactions.[41] This situation has created tension between nurses, who

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TABLE Cases Presented and Major Themes

Case Study	Major Themes	Symptoms
A 24-year-old woman with osteosarcoma	• Loss of dignity, autonomy • Feelings of self-blame • Declined surgical treatment to amputate a limb, which might have improved her quality of life • Unfulfilled desire to see her child again	• Dyspnea • Pain • Edema • Skin erosion • Lymphedema • Depression
A 45-year-old woman with metastatic lung cancer	• Spiritual distress • Autonomy regarding decision-making/end-of-life care • Sedation related to opioids • Family tension • Regret at not being present as a mother to her daughter	• Pain • Fatigue • Insomnia • Cachexia/weight loss • Sedation • Anxiety, panic
A 78-year-old woman with metastatic breast cancer	• Fear of dying alone	• Pain • Dyspnea • Lymphedema
A 43-year-old man with glioblastoma	• Heavy symptom burden • Severe anxiety and depression	• Pain • Hemiparesis • Urinary incontinence • Fever • Insomnia • Vision changes • Ageusia
A 45-year-old man with glioblastoma	• Denial regarding diagnosis/prognosis • Communication challenges • Palliative sedation—when to use	• Pain • Shortness of breath/ secretions • Nausea/anorexia/ dysphagia • Weakness/sedation • Constipation
A 35-year-old man with colon cancer	• Heavy symptom burden • Socioeconomic challenges • Patient accepting diagnosis; family not able to accept reality of poor prognosis; family distress	• Pain • Nausea/vomiting/ anorexia • Ostomy care
A 42-year-old woman with ovarian cancer and COVID-19	• Benefit versus burden of transfusions • End of life decision-making • Spiritual needs	• Pain • Dyspnea • Fatigue • Ascites • Edema
A 57-year-old man with pancreatic cancer	• Family request to control pain using only intramuscular diclofenac due to fear of opioids • Family would not allow conversations regarding palliative care/ declining recommendations from team • Patient withdrawn/angry • Family emotions/anger/conflict with team	• Pain • Fatigue • Insomnia

are concerned with substandard efficacy and unresolved pain, and physicians who are reluctant to prescribe more potent opioids when patients report severe pain.

Other sources of conflict between nurses and physicians on the palliative care teams is the frequent need for adjustment and titration of opiates to provide optimal pain control in patients with severe pain crises. Nurses who have attended ELNEC and other palliative training courses may have more current information about pain treatment from a variety of international guidelines, yet some physician colleagues have not received this education. Further, although widely accepted for patients with severe pain in the United States, methadone has not yet been adopted into practice in CEE/CA countries.[42-44]

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At times members of the palliative care team (particularly nurses and physicians) do not agree on the realistic objectives of care provided and discussed with the patients and families. Nurses in these countries are often not empowered to openly disagree or further discuss concerns once the physician has determined the plan of care, yet they are most often in the home or at the bedside charged with implementing the plan. Established hierarchies within health care do not allow nurses to make recommendations to their physician colleagues, or their suggestions are not accepted. In fact, there is risk that nurses may lose their positions if they approach a physician colleague with concerns about the plan of care. The traditional role of the nurse is to be subservient, and rigid health care systems do not foster collaboration. Despite these challenges, the participants noted with some optimism that the number of physicians who welcome nursing collaboration is slowly growing.

Moral Distress

Moral distress occurs when professionals feel powerless to provide high-quality palliative care.[45] Nurses in this study reported distress at limited communication about end-of-life care, inadequate relief of pain and other symptoms, and insufficient staffing. Inequity due to lack of resources is another source of moral distress.[46,47] In all cases presented, there were social aspects that substantially increased the moral distress experienced by the participants. Poor living conditions, the lack of financial resources of the families, the absence of materials needed for wound care (eg, fungating tumors, lymphedemas), and inadequate technical support that would be available in other parts of the world for similar patient (eg, community care available 24/7, inpatient hospice care, access to needed equipment) all caused moral distress.

Finally, strong emotions expressed by family were on occasion a source of moral distress for the palliative care team. Patient or family guilt and fear were often manifested as anger; this anger was frequently misdirected to the palliative care nurse and other team members in the home. This created distress for professionals attempting to provide empathic, supportive care.

DISCUSSION

This novel, online, interactive, case-based educational offering provided a method to allow ongoing integration of palliative care principles for health care professionals who attended the ELNEC/OMI course in Salzburg. These discussions based on challenging patient cases were highly rated by participants who strongly voiced that the interactions would change their clinical practice to positively impact patient care. Cost-effectiveness was another significant advantage of this delivery method.

These case conferences provided an opportunity for palliative care staff to discuss concerns, share frustrations, and provide guidance to colleagues from around the world. Many of the challenges encountered providing palliative care are universal. Through case vignettes, the group has been able to offer specific interventions, advances in practice, and discussions of approaches toward family and other health care professionals to provide optimal care. The participants also report that the opportunity to learn from and support peers in other countries has been a rewarding and emotionally uplifting experience.

The themes identified during the teleconferences, including ethical dilemmas, communication concerns, and moral distress, are universal challenges experienced by those working in palliative care.[48-50] To know that others face these same obstacles can provide comfort, especially when clinicians may feel isolated in their roles. Palliative care is uniquely challenging with constant exposure to death, loss, and grief; attendees offered emotional support to one another during these discussions that is more authentic knowing they, too, live through this work.

There were challenges associated with the teleconferences. Lack of English proficiency for some of the participants resulted in limited interactions and prohibited their contributions to the discussion. Finding times that were acceptable for all given different time zones was another obstacle, with participants trying to balance work and home responsibilities.

In the future, this international group intends to continue these educational efforts. The group recognizes the responsibility of coordinating large numbers of professionals and plans to engage more individuals in leading the management of these sessions. We also hope to give each country an opportunity to present difficult cases while assisting them in these presentations. Given the amount of data shared through the discussion of these 8 cases, we are exploring starting a shared online platform to house clinical information and relevant scientific literature so that all participants will have access to accurate, evidence-based data. In recognition of the recurring themes noted during these discussions, we also intend to propose creation of protocols, procedures, or other tools that can be adapted to local settings, to empower palliative care nurses and other professionals to practice in concordance with international guidelines, as well as to protect their roles from common ethical dilemmas.[51]

For learning to influence change in palliative clinical practice, education needs to be ongoing, incorporating specific interventions targeted to the learner, in a format that enhances knowledge and networking.[52,53] Monthly teleconferences using difficult case discussions between peers, with mentors' facilitation and supervision, can be a mechanism for deepening theoretical information, allowing incorporation of best practice into the clinical setting and, ultimately, improving care for all with serious illness.

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