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Integrating Palliative Care into Nursing Care

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Abstract

The need for palliative care in our health care system has exponentially increased in the past few years as a result of the COVID-19 pandemic, the aging population, and the increasing number of people living with serious illnesses. While nurses play a critical role in delivering palliative care, many lack confidence and knowledge, causing practice gaps in the clinical and psychological management of seriously ill patients. The collective burden of the pandemic has demonstrated the importance of palliative care education and training, specifically in communication, symptom management, and continuing education. All nurses, including nursing students, transitioning nurses, and practicing nurses, should be trained to offer generalist (or primary) palliative care, in accordance with the American Association of Colleges of Nursing *Essentials: Core Competencies for Professional Nursing Education*. Provision of holistic, relationship-based, and integrated palliative care for patients and their families is an ethical obligation for all nurses.

Keywords

COVID-19; end-of-life care; nursing; nursing education; nursing workforce; palliative care

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Lessons from the COVID-19 pandemic can help change nursing care for patients living with serious illnesses.

Evidence over the last decade has shown that the early integration of palliative care—a person- and family-centered approach that addresses the physical, functional, psychological, practical, and spiritual consequences of serious illness¹—is essential to improved outcomes.^{2, 3} Therefore, access to universal palliative care is—and will continue to be—a crucial component of optimal health care.^{4, 5}

However, the ongoing COVID-19 pandemic—along with the growing numbers of older people and of those living with illnesses such as dementia and cancer⁶—has culminated in an unprecedented need for palliative care,^{2, 7} one that far exceeds the capacity of specialty palliative services.⁸ This has made the provision of generalist (or primary) palliative care—supportive care delivered by health care professionals not trained as palliative care specialists—a clinical imperative.^{1, 9}

Nurses, who make up the largest part of the health care workforce, play a critical role in the delivery of primary palliative care. But evidence suggests that they lack confidence in their ability to do so.¹⁰ This practice gap has only widened during the COVID-19 pandemic, when even experienced nurses have been challenged by the complex clinical management of a novel virus, and newly transitioned nurses with limited training have experienced the added pressures of caring for high-acuity patients.¹¹

This article highlights the need to integrate palliative care into nursing education and practice and offers recommendations for an enhanced delivery of primary palliative care.

THE ESCALATING NEED FOR PALLIATIVE CARE

Throughout the pandemic, nurses have overcome tremendous challenges in addressing patients' palliative care needs despite a lack of formal palliative care training. At the same time, the pandemic has revealed specific primary palliative care deficiencies among practicing nurses, including difficulty addressing the psychological demands of serious illness (through effective communication, for example) and its physical manifestations (through expert symptom management).

Communication.

The need to align patients' wishes with their rapidly changing health conditions has brought to light the importance of early communication regarding palliative care. But nurses—who have been responsible for conducting vital conversations about advance care planning, resuscitation status, and transitions of care¹²—have faced communication challenges caused by systemic barriers such as isolation protocols and visiting restrictions,¹³ as well as by their own discomfort discussing palliative care.¹⁰ To address this gap, specialty palliative care nurses have stepped in to facilitate communication with patients and families on such topics as the goals of care, the illness trajectory, hopes and expectations, prognosis, life-sustaining treatments, hospice, and end-of-life care.^{12, 14} This has resulted in the development of communication scripts, guides, and virtual training programs for primary palliative care

providers across various acute- and community-based health care settings, along with several critical tools and resources. (See Table 1.^{15, 16})

Throughout the pandemic, as in-person visits abruptly transitioned to virtual platforms, telehealth played a significant role in facilitating communication. Nurses quickly adapted to communicating through audiovisual technologies while maintaining the relational aspects of communication. Family meetings conducted through such virtual platforms as Zoom and WebEx allowed for the increased involvement of caregivers in shared decision-making. Consequently telehealth, which makes health care accessible to patients regardless of geography,¹⁷ is now becoming increasingly accepted in the delivery of clinical care. However, barriers such as lack of internet access and limited clinician training in virtual communication^{18, 19} need to be addressed to optimize telehealth care delivery beyond the pandemic.

Expert symptom management.

The pandemic also underscored the profound need for nurses to reduce suffering through symptom management.²⁰ As a result, several resources were rapidly created.²¹ For example, the American Association of Colleges of Nursing (AACN) designed the End-of-Life Nursing Education Consortium (ELNEC)—a COVID-19 resource center where nurses can access tools for the management of COVID-19 symptoms, including dyspnea, pain, cough, anxiety, and delirium.²⁰ However, while these resources have been supportive, nurses may have difficulty integrating these tools into practice without further guidance or training.

THE IMPORTANCE OF CONTINUING EDUCATION

Since palliative care is not always included in formal nursing education, access to continuing education is critical. However, many nurses are deterred from pursuing continuing education because of obstacles such as time constraints (caused by scheduling issues and short staffing) and limited resources within health care systems (particularly among rural and publicly funded hospitals).

Work environments must facilitate access to continuing education by partnering with educational resources or forming practice–academic relationships to provide training opportunities to practicing nurses.^{22, 23} These educational offerings must be made flexible, allowing nurses to access web-based, on-demand resources such as tele-mentoring, videoconferencing, or virtual simulations regardless of their location or work schedule. One caveat remains: as some evidence suggests that exclusively online approaches may not be optimal in achieving palliative care competencies,²⁴ continued research is necessary to determine the impact of virtual learning on patient outcomes.^{23, 25}

Another important factor in palliative care education is its delivery across various health care settings. Critical care nurses need tools to enable early integration of palliative care in order to facilitate the transition from aggressive care to comfort and allow for a natural death.²⁶ And as health care systems increasingly shift to outpatient community-based care, practice–community partnerships should jointly train acute care and outpatient nurses,^{27, 28} as this will increase the provision of early, tailored primary palliative care in community-based

settings. To ensure professional growth among practicing nurses, such continuing education offerings should be built into promotional incentives.²⁹

FORMAL INTEGRATION OF PALLIATIVE CARE INTO NURSING EDUCATION

Palliative care content is an emerging curricular imperative in nursing education, holding significance for bridging the education-to-practice gap among nursing students as well as novice nurses transitioning to practice.

Nursing students.

The AACN *Essentials: Core Competencies for Professional Nursing Education*—a document created to provide a framework for improving the quality of nursing education—outlines the content and competencies nursing students should be familiar with upon graduation. The *Essentials'* newest recommendations include the development of competencies in four spheres of care, with hospice/palliative/supportive care being one of those spheres. Thus, nursing programs are being compelled to formalize palliative content in their curricula, a practice that has been largely lacking.³⁰

Until now, beyond ad hoc approaches, the most prevalent palliative care training for nursing students has been the ELNEC, which provides education and resources on the incorporation of palliative care into nursing practice. Nearly 1,000 undergraduate and graduate schools of nursing have integrated ELNEC modules into their curricula.³¹ However, deficiencies remain, and many nursing programs lack this training. The adoption of ELNEC as a standard for undergraduate and graduate curricula is needed now more than ever to comply with the AACN *Essentials* and to help nurses improve their palliative care skills.

Prior to granting entry into practice, nursing programs may also consider using palliative care skills assessments to ensure that students' proficiency extends beyond textbook knowledge to include hands-on performance.³² Assessments may be conducted through such measures as the Palliative Care Nursing Self-Competence Scale or the CARES Perceived Competence instrument.^{33, 34} Demonstrating these cognitive, affective, and psychomotor skills may enhance nurses' confidence and competence as they enter into practice.³²

It is also important to remember that interdisciplinary collaboration among primary and specialist palliative care providers—an essential aspect of palliative care delivery¹—often occurs over time and attends to patient needs across care settings (see *A Palliative Care Case Study*). To help nursing students to learn with, from, and about their colleagues, interprofessional training and simulation should be considered.³⁵

Transitioning nurses.

As nurse residency programs increasingly move toward standardization and accreditation,^{36, 37} the AACN *Essentials* highlights the need for updating the standards of these programs. Novice nurses are routinely placed in residency programs to help them transition into the health care system, but opportunities for immersive palliative care learning experiences are rare. Still, exemplars for such efforts exist.³⁸ New York City-based Calvary Hospital, for instance, has a 12-month specialized palliative and end-of-life care

residency program for recent graduates and early to mid-career nurses. Care Dimensions in Massachusetts also offers a hospice nurse residency program that includes lectures, simulations, field observations, and preceptorship. Some studies have demonstrated that palliative-focused, interprofessional, and simulation-based education may be more effective in providing interprofessional competencies than palliative-specific knowledge,³⁹ suggesting the need for repeated exposure to palliative care scenarios upon entry into practice. Such exposure will help address any deficiencies in nurses' didactic or clinical education. It may also help nurses gain the knowledge and skills necessary for providing quality primary palliative care, both of which are insufficient among those who have been practicing for less than a year.⁴⁰ To provide these training opportunities, health systems should partner with academic institutions, leveraging shared resources and simulated palliative care scenarios.^{41, 42}

Finally, it must be noted that throughout the COVID-19 pandemic, transitioning nurses have been encountering patient deaths and ethical dilemmas more frequently than they typically would. Opportunities to formally debrief in a safe, supportive space about patients' complex palliative care needs with other nursing staff, palliative care experts, or ethics committees may not only help with the development of adaptive coping behaviors,⁴³ but may also serve as critical teachable moments.⁴⁴

CONCLUSION

To ensure the dignity and quality of life of people with serious illnesses, palliative care should be fully integrated throughout health care,⁹ especially as the COVID-19 pandemic continues. Given the shortage of specialist palliative care providers, proficiency in palliative care is an ethical obligation for all nurses. This is an opportune time for nursing programs to embed palliative care curricula into baccalaureate, master's, and doctoral programs, using the newest recommendations from the AACN *Essentials*. Practicing nurses and transitioning nurses should also have access to palliative care education and training and recognize the need for specialist palliative care consultation when appropriate.^{45, 46}

The collective burden of the pandemic—a time of increased loss and ethical dilemmas—has demonstrated the importance of palliative care education and the need to improve nursing care for patients with serious illnesses and their families.

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A Palliative Care Case Study

An interdisciplinary team helps ensure a patient's wishes are met at the end of life.

Jonathan Rodriguez was a 25-year-old man with a history of refractory acute myeloid leukemia. He lived with his mother and stepfather—his primary caregivers who are Spanish speaking—and his dog. His Christian faith was important to his coping with his illness. Mr. Rodriguez received a matched related donor allogeneic transplant, with his older brother as the donor.

Shortly into his posttransplant recovery, Mr. Rodriguez developed painful mucositis, nausea, anxiety, and insomnia, for which Kathleen Thomson—his primary oncology nurse—suggested a palliative care consult. Mr. Rodriguez was started on hydromorphone intravenous patient-controlled analgesia, antiemetics, and an anxiolytic to help him sleep. Although his pain was better, he became withdrawn, spending more time in bed. Ms. Thomson requested that the palliative care social worker meet with him.

The social worker formed a therapeutic relationship with Mr. Rodriguez, who disclosed his anger at God, his fear of being a burden to his family, and his worries about how the family would manage after his death. The palliative care chaplain also met with Mr. Rodriguez, exploring his existential distress and the role of faith in his illness. Mr. Rodriguez was eventually discharged on oral hydromorphone and received follow-up care from the outpatient palliative care team. However, one year after the transplant, the leukemia relapsed. It was determined that Mr. Rodriguez was not a candidate for a second bone marrow transplant. He was enrolled in two different clinical trials, both failing to control the leukemia.

Mr. Rodriguez was rehospitalized for sepsis, bleeding, and further disease progression in the liver and spleen. When Ms. Thomson explored Mr. Rodriguez's understanding of his illness, he responded, "I don't know what to expect. I just want to get better." She organized a meeting with Mr. Rodriguez, his family, a Spanish interpreter, and the interdisciplinary team. The oncology team explained that Mr. Rodriguez was no longer a candidate for further cancer-targeted treatments and that his prognosis could be short given the sepsis and complications of the disease. After discussion with the team and his family, Mr. Rodriguez decided to allow a do-not-resuscitate order. His parents were initially upset by this; however, after hearing Ms. Thomson reframe this decision not as an indication of "giving up," but as their son's desire to avoid additional suffering that might not extend the quantity or quality of his life, they began to adopt a different view.

When, after several days, it became clear that Mr. Rodriguez's condition was not improving, he and his parents understood that his illness would not be reversed. He expressed to Ms. Thomson his wish to be home with his family and his dog, especially for the end of his life. Ms. Thomson shared this with the palliative care team, and they met with Mr. Rodriguez and his family to discuss transition options to facilitate care at home. Discharge with home palliative care services was organized so Mr. Rodriguez could continue transfusions as he spent his remaining time with his loved ones. Two

weeks after his discharge, Mr. Rodriguez decided to transition care to hospice and he died at home, surrounded by his family.

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Table 1.

Nursing Resources for COVID-19 and Palliative Care

| Resource | Description |
|--|---|
| AACN ELNEC Resource Center | A resource center created to support nurses during COVID-19 containing information on communication, culture, final hours, geriatric and long-term care, loss, grief and bereavement, pediatric care, primary palliative care, self-care, and symptom management. www.aacnnursing.org/ELNEC/COVID-19 |
| CAPC COVID-19 Rapid Response Resources Hub | A resource site for clinicians to assist with communication, symptom management, emotional PPE (coping, self-care, grief), palliative care team organization, telehealth, waivers, home and long-term care, patients and families, health equity, and end-of-life issues. www.capc.org/covid-19 |
| NICHE COVID-19 Resources for Patients and Caregivers | A comprehensive list of resources containing vaccination toolkits, COVID-19 tip sheets, information on ageism and COVID-19, and self-care guides. https://nicheprogram.org/resources/COVID-19 |
| Vital Talk: COVID Ready Communication Playbook | Created by Vital Talk, a program of evidence-based trainings on communication for serious illness, the COVID Ready Communication Playbook compiles scripts and tips for clinicians. There are also video examples, supplemental scripts, and collaborative resources from Vital Talk faculty. www.vitaltalk.org/covid-resources |
| Harvard Palliative Care Toolkit ¹⁵ | Developed by an interdisciplinary group at Harvard, the Palliative Care Toolkit provides expert and evidence-based guidance on serious illness communication. <ul style="list-style-type: none"> • It is accessible through multiple platforms, including web and mobile applications, quick guides, pocket cards, and videos. • Training videos include information on goals of care, code status, and end-of-life conversations. • A resource hotline, staffed by palliative care nurses, is available 24/7 to assist nonpalliative care clinicians and advise bedside nurses. • Also contains one-page summaries and online protocols for managing common COVID-19 symptoms. |
| Telehealth Rapid Response Team ¹⁶ | The Telehealth Rapid Response Team was implemented by New York City Health and Hospitals, one of the largest U.S. health care delivery systems, to guide workflows, engage clinical teams, procure software and hardware, identify billing issues, and address legal and compliance issues. Patients and providers could complete assessments, diagnose, plan, implement interventions, and evaluate outcomes while complying with quarantine safety mandates through this system. |

AACN = American Association of Colleges of Nursing; CAPC = Center to Advance Palliative Care; ELNEC = End-of-Life Nursing Education Consortium; NICHE = Nurses Improving Care for Healthsystem Elders; PPE = personal protective equipment.