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Primary Palliative Care Clinical Implications:

Oncology nursing during the COVID-19 pandemic

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Abstract

The COVID-19 pandemic continues to affect the health and well-being of individuals and communities worldwide. Patients with cancer are particularly vulnerable to experiencing serious health-related suffering from COVID-19. This requires oncology nurses in inpatient and clinic settings to ensure the delivery of primary palliative care while considering the far-reaching implications of this public health crisis. With palliative care skills fully integrated into oncology nursing practice, health organizations and cancer centers will be better equipped to meet the holistic needs of patients with cancer and their families receiving care for serious illness, including improved attention to physical, psychosocial, cultural, spiritual, and ethical considerations.

Keywords

primary palliative care; quality of life; COVID-19; pandemic; end-of-life care

The COVID-19 crisis is having profound consequences on the integrity of healthcare delivery and the nursing workforce around the world. Resource constraints, ethical dilemmas, spiritual and existential distress, increased visibility of health inequities, and social isolation are just some of the issues affecting patient, family, caregiver, and palliative care–related outcomes (Abedi et al., 2020; Dawson et al., 2020; Emanuel et al., 2020; Ferrell et al., 2020; Marmot, 2020; Morley et al., 2020). Patients with cancer are particularly vulnerable to COVID-19 and at increased risk for serious symptomatic complications and

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rapid physical decline (Mehta et al., 2020). In addition, there are a number of factors that may influence oncology nurses' care of patients with cancer in the context of COVID-19, including the stage and aggressiveness of the patient's cancer, the availability of resources for care (e.g., personal protective equipment, staffing, medications), increasing COVID-19–related anxiety, and the management of cancer amid an overwhelmed healthcare system.

The purpose of this article is to equip clinical oncology nurses working in all settings with primary palliative care skills during the COVID-19 pandemic. The End-of-Life Nursing Education Consortium (ELNEC, 2020a) is an international palliative care education initiative that has empowered more than one million nurses globally with palliative care skills and competencies. This article provides an evidence-based resource for primary palliative oncology nursing created by an ELNEC task force in response to the pandemic.

Palliative Care During the COVID-19 Pandemic

The increasing global prevalence of COVID-19 and associated deaths have called urgent attention to the critical nature of integrating palliative care throughout the healthcare continuum (De Lima et al., 2020; Radbruch et al., 2020). Palliative care is a critical component of high-quality health care, and access to it has become more significant during the COVID-19 pandemic. Available, affordable, accessible, and culturally acceptable health care is a right of all individuals, regardless of financial, social, political, geographic, racial, religious, or other considerations (American Nurses Association [ANA], 2016; International Council of Nurses, 2011; Knaul et al., 2018). Universal palliative care access is recognized as a core aspect of universal health coverage (World Health Organization, 2014, 2019).

With more than 114 million cases of COVID-19 worldwide (Johns Hopkins University, 2020), oncology nurses are integral to alleviating serious health-related suffering and optimizing quality of life for patients facing competing priorities related to the pandemic and the broad impacts of cancer. Throughout COVID-19, oncology nurses have had to promote simultaneous discussions about cancer management in the context of this public health emergency, mitigate the risk for contracting COVID-19, and plan for subsequent health-related crises. Advance care planning has become particularly important during the pandemic because of visitor restrictions and other factors that may challenge the integrity of the cancer care experience.

To ensure person-centered oncology care throughout the COVID-19 pandemic, it is imperative to provide primary palliative nursing education on communication skills for advance care planning and general pain and symptom management (Mehta & Smith, 2020). The following recommendations can be applied to oncology nursing:

- Increase palliative care education for oncology nurses to ensure palliative care begins at the time of diagnosis and encompasses additional concerns related to COVID-19.
- Safely expand the scope of practice and leadership roles commensurate with training and education to support oncology nurses on the front line in clinics and

acute care settings to provide palliative care within the changing landscape of the COVID-19 pandemic.

- Provide resources and support for oncology nurses' self-care and to build resilience.
- Promote a palliative care lens in oncology nursing science and research as it relates to caring for patients during the COVID-19 pandemic and beyond.
- Ensure palliative care priorities are integrated early and throughout the cancer care continuum, with particular attention paid to the COVID-19 context.

All patients with cancer require primary palliative care to systematically address physical, psychological/psychiatric, social, spiritual/religious/existential, cultural, end-of-life, and legal and ethical needs through an inherently interprofessional approach to care planning and delivery (Chow & Dahlin, 2018; Dahlin, 2015; Ferrell et al., 2017; Kaasa et al., 2018; Oncology Nursing Society [ONS], 2019; Rosa et al., 2020). Primary palliative care should be prioritized by all members of the healthcare team and begin at diagnosis of cancer (American Society of Clinical Oncology, n.d.; Kaasa et al., 2018; National Coalition for Hospice and Palliative Care [NCHPC], 2018; ONS, 2019). In addition, with the potential risk for contracting COVID-19, all individuals deserve to have clinical discussions about the virus as a potentially fatal condition with significant debilitating sequalae. Primary palliative nursing competencies for the RN and advanced practice RN should be integrated into all aspects of oncology nursing (American Association of Colleges of Nursing, 2016, 2019; ELNEC, 2020b; ONS, 2019). Oncology nurses need coaching and mentoring around communication, common pain and symptom management, community resources, and planning within the confines of COVID-19. By assessing, evaluating, and deliberately striving to meet palliative needs early in the care plan of patients with cancer, oncology nurses play a key role in ensuring effective symptom management, eliciting patient values and preferences, providing advance care planning and documentation, and partnering with palliative specialists when and where available, among other vital interventions (Hospice and Palliative Nurses Association [HPNA], 2020) (see Figure 1).

ELNEC Resources for Primary Oncology Nursing

To best support nurses during the pandemic, ELNEC (2020b) formed a task force of palliative nursing specialists to create evidence-based tools and resources to aid in optimizing palliative care delivery across a host of settings (www.aacnnursing.org/ELNEC/COVID-19). These resources can be easily accessed online and downloaded for personal, institutional, educational, or patient and stakeholder education purposes to advance the field of palliative nursing. Through a series of webinars, video lectures, guides, and other presentation forums, the ELNEC team provides direction for palliative nurses on symptom management; loss, grief, and bereavement; meeting cultural needs; communication; end-of-life care; nursing self-care; and the delivery of primary palliative care during a disaster.

Primary palliative nursing is essential to ensuring person-centered, holistic care in the COVID-19 oncology milieu (ELNEC, 2020b; HPNA, 2020; ONS, 2019). A series of infographics were created to provide strategic applications of primary palliative oncology

nursing across all eight domains of quality palliative care according to NCHPC (2018) clinical practice guidelines. A modified version of the primary palliative nursing tools was compiled for this article to guide oncology nurses in delivering primary palliative nursing care safely, critically, and efficiently to all patients, particularly those receiving acute care services (see Figure 2).

Alleviating Suffering

Suffering for patients can be relieved by addressing the eight domains of palliative care strategically and regularly and by integrating primary palliative care skills. This is more challenging during the COVID-19 pandemic because of the added stress and concerns it brings to oncology care.

Tenets identified by Ferrell and Coyle (2008) can assist with guiding the integrity of nursing practice during COVID-19 while addressing the suffering experience of those with serious illnesses. Examples of primary palliative oncology nursing interventions to alleviate suffering include the following:

- Assessing patients for the suffering associated with multiple losses at the intersection of cancer and the psychosocial consequences of COVID-19: Expert communication skills are necessary to promote connection and mitigate isolation (e.g., use of therapeutic verbal and nonverbal techniques).
- Being present to patients' search for meaning or answers during their illness: Oncology nurses must listen to patients with compassion and collaborate with appropriate interprofessional team members; the importance of empathically bearing witness to the patient and family experience cannot be understated.
- Considering all potential sources of suffering: Oncology nurses must assess for hopelessness, provide spiritual care support, acknowledge spiritual distress, and consult with spiritual care specialists.

Acknowledging and attending to suffering is not only a goal of primary palliative care but an ethical foundation of nursing (ANA, 2015; Ferrell & Coyle, 2008). Considering these aspects of suffering can inform oncology nurses about the broad and sometimes unseen variables that cause distress and disharmony at physical, psychological, social, and spiritual levels.

Case Study

Mary is a 54-year-old woman with metastatic colon cancer. During a previous clinic visit, her oncology nurse initiated conversations about advance care planning related to her cancer diagnosis and COVID-19. However, Mary had been reluctant to talk about any disease progression.

Mary is admitted with symptoms of recurrent shortness of breath and tests positive for COVID-19. Her respiratory symptoms require supplemental oxygen via nasal cannula, and she is placed on airborne precautions. Hospital visitors are restricted because of the pandemic. After several days, Mary's symptoms worsen, requiring placement of a

nasogastric tube and increased oxygen support. Most providers are working remotely or decreasing face-to-face interactions with patients and relying on the expertise of the bedside oncology nurses to facilitate symptom assessment and goals-of-care conversations. Mary expresses that she is afraid of dying and asks her night shift nurse, Ben, “What has my life really meant?” Ben and his team understand their vital role in ensuring a quality end-of-life experience for Mary and her loved ones. They apply a systematic approach to effectively meet her and her families’ palliative care needs within the limitations of the COVID-19 pandemic.

Mary died a few days following her admission. Her oncology nurses, in consultation with the palliative care team, made recommendations based on the rapport built with Mary and her family through primary palliative nursing. The oncology nurses, including Ben, were able to advocate for Mary’s family to visit once she decided to decline further disease-modifying treatment and focus exclusively on symptom management. They provided anticipatory bereavement support for the family, spiritual care for Mary, and ensured meticulous attention to Mary’s preferences throughout the rest of her life. The nursing team felt satisfied that their care allowed Mary to have a dignified death with minimal physical, psychosocial, and spiritual suffering.

Conclusion

Holistic, humanistic care has long been the foundation of palliative care. All oncology nurses are in a unique position to advocate for patients regarding access to and the delivery of quality palliative care (ONS, 2019). Oncology nurses must be educated and trained to incorporate palliative care skills into their clinical practice given the chronic nature and severity of many cancers, as well as to consider the trajectory of various cancers, manage common pain and other symptoms, and initiate advance care planning about goals of care. With the COVID-19 pandemic, oncology nurses must have additional palliative care training to advocate for their patients with cancer and help them to make informed choices about their care.

COVID-19 has increased anxiety and isolation and reduced contact to healthcare providers, support systems, and sometimes family. These factors necessitate that oncology nurses serve as skilled communicators to help elicit patient’s values and preferences for cancer care and then determine how those values and preferences might change if the patient develops COVID-19. ELNEC has developed tools that help oncology nurses have easy access to pain and symptom management evidence, communication techniques, and cultural sensitivity education. These resources empower oncology nurses to attend to the physical, psychosocial, cultural, spiritual, and ethical considerations of patients with cancer and other serious illnesses.

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AT A GLANCE

- Palliative care is an integral component of comprehensive cancer care throughout the illness trajectory.
- COVID-19 has increased the burden of serious health-related suffering for patients with cancer, requiring enhanced primary palliative oncology nursing skills.
- Oncology nurses should integrate primary palliative care skills while considering the myriad psychosocial, physical, and spiritual consequences of COVID-19.

PRIMARY PALLIATIVE NURSING CARE

- Understand the trajectory of cancer conditions and critical decision-making points, as well as the potential for COVID-19 to exacerbate symptoms because of immunosuppression. Support patients whose treatment and diagnostic surveillance was put on hold during COVID-19 surges.
- Understand the risk for patients with cancer in contracting COVID-19, minimize transmission with PPE, and simultaneously promote dignity and personhood.
- Manage and treat common cancers and provide symptom management and end-of-life care, which must be based on evidence, amid medication shortages and the use of telehealth.
- Discuss advance care planning, goals of care, and issues of advanced disease, and provide psychosocial support for patients and their families of varying cultures regarding the type of cancer and the higher risk of poor outcomes if a patient develops COVID-19.
- Understand hospice and palliative care services, the patient's eligibility, and how to access these services in the patient's setting and community, as well as their capabilities to care for patients with COVID-19. Many hospices, home health agencies, and home-based programs have been modified or have changed capacity because of inabilities to secure PPE or changes in staffing.
- Attend to population-specific concerns across the lifespan, such as pediatric and geriatric oncology palliative care during the COVID-19 pandemic, including addressing social isolation and lack of informational support from families during treatment, among others.
- Understand community resources for patients with cancer and their adaptation of programs during the COVID-19 pandemic, which may include telehealth. However, patients may lack resources, such as smart devices or Internet access to use devices, or they may need support to effectively use technology platforms for telehealth visits.

SPECIALTY PALLIATIVE NURSING CARE

- Acquire knowledge about pathophysiology of diseases, pain and symptom management, counseling, and communication skills pertinent to patients with cancer.
- Understand which cancers may put an individual with COVID-19 at increased risk for severe disease. Help patients to consider cancer treatment options and understand how COVID-19 surges may change their treatment plan because of available resources.
- Possess advanced knowledge about the care of individuals with serious and life-threatening illness, such as cancer, and those who are imminently dying, including understanding community resources for patients who prefer to stay at home with their families instead of in the hospital where they may be alone because of visitor restrictions. In addition, nurses must be aware of available medications and equipment, which may vary because of regional shortages.
- Manage complex pain and symptoms related to cancer being treated with sophisticated regimens. During the pandemic, community-based care and rural hospitals may not have the capacity to manage complex issues. Patients may need to choose whether to transfer their care and be isolated from their families or to stay in geographic proximity to home.
- Use expert communication skills with patients to explore quality of life, illness understanding, informed decision-making, conflict negotiation, or advanced disease in terms of their cancer diagnosis within the context of COVID-19 while also discussing the goals of care should the patient contract COVID-19.
- Organize a plan for a patient's death in terms of setting, proactive pain and symptom management, and education about the dying process for the patient, family, and staff with regard to potential challenges from COVID-19. It is necessary to discuss the resources for patients if they stay at home (telehealth versus in-person) based on availability of PPE, personnel, and equipment. If the patient is in an acute care facility, there may be limited access for family and a risk for social isolation.
- Direct transitions of care across health settings. For patients with cancer and their families, ensure continuity of care throughout the COVID-19 pandemic. Oncology nurses can ensure quality care and transitions through telephone calls to patients to confirm access to support, medications, equipment, and personnel.
- Provide psychosocial and emotional support and presence to patients and families throughout the illness trajectory. Because of visitor restrictions, some social workers are offsite, and families are not allowed to visit acute care facilities or clinics. Therefore, oncology nurses must assess and meticulously attend to psychosocial and emotional aspects of care.
- Attend to cultural and spiritual dimensions of care as specified by the patient and family. The COVID-19 pandemic has highlighted disparities across health systems. In addition, spiritual providers are carrying the heavy burden of caring for both staff and patients during the pandemic. Oncology nurses must assess culture and spirituality to create a plan of care for individuals with cancer while considering COVID-19.

FIGURE 1. PRIMARY AND SPECIALTY PALLIATIVE ONCOLOGY NURSING CARE DURING THE COVID-19 PANDEMIC

PPE—personal protective equipment

Note. Based on information from American Nurses Association & Hospice and Palliative Nurses Association, 2017; Dahlin, 2015.

DOMAIN 1: STRUCTURE AND PROCESSES OF CARE

The move toward telehealth may complicate involvement of cancer specialists and interprofessional providers. Family engagement may look different across family units and settings. Technology is playing an increased role in family–provider communication, but some families do not have access to or cannot afford the necessary technology and may require strategic planning with loved ones and designated proxies for health care. Care coordination and continuity will require an interprofessional team and constant planning to ensure access to needed services.

- What is your understanding of the purpose of this visit and its relationship to your current treatment for your cancer?
- What are your concerns related to this hospitalization and/or your current treatment?
- Has the COVID-19 pandemic raised any worries or fears about your cancer care that you would like to discuss?
- Many of our providers are working virtually at this time. To best care for you, we use an interprofessional team to care for your physical, emotional, and spiritual needs. When would be the best time for social work, chaplaincy, and volunteers to contact you and your family?
- What is the best technology for us to use to contact you—landline telephone, mobile phone, or email?

DOMAIN 2: PHYSICAL ASPECTS OF CARE

The context in which physical, emotional, and spiritual well-being is defined has evolved during the pandemic and has been affected dramatically for many people and populations, including patients with cancer. Pain and symptoms may be underreported or dismissed by patients or undertreated by health providers because of patient or family concerns about COVID-19 exposure, and needed care may be delayed. Patients with cancer on long-term opioid regimens may require additional or higher-dose opioids to manage pain symptoms, breathlessness, or new pain/dyspnea associated with COVID-19. Quality of life may have taken on new meaning for patients with cancer during the pandemic.

- What have been your usual treatment and visit schedules? Do you still have symptoms?
- Given your comfort level, what is the best way to have regular visits—in-person or virtually?
- Do you have any changes in any symptoms, including fatigue and anxiety, at this time?
- What symptoms are bothersome to you at this time (e.g., pain, shortness of breath, indigestion, fevers, sleeplessness, nausea, constipation)?
- What treatments have you been using at home that have been effective? Which ones have you tried that have been ineffective?
- To family members: Are there any other symptoms you have observed that we should be aware of?

DOMAIN 3: PSYCHOLOGICAL AND PSYCHIATRIC ASPECTS OF CARE

Social isolation has exacerbated existing mental health conditions, such as depression and anxiety, requiring ongoing input and assessment from specialists. Fear, worry, and other distress associated with COVID-19 have sparked new mental health challenges for patients with cancer and their families. However, some patients with cancer may have existing coping skills for isolation because they needed to be careful due to their immunocompromised status pre-pandemic. Family dynamics may have become more complex in the context of cumulative loss and grief; additional social work and chaplaincy may be needed. Mental health support may be required long-term beyond acute situations, such as hospitalization; consider a plan upstream to promote continuity and coordination of care at discharge.

- Can you tell me about how COVID-19 is affecting your mood or spirits? How has it has affected your sense of well-being?
- Have any of your loved ones been ill with COVID-19? How has that affected you?
- Have you experienced any losses of family members or loved ones during the COVID-19 pandemic?
- How do you cope? Where do you find support? Who do you turn to?
- Do you feel you would benefit at this time from additional support from our [social workers, chaplains, volunteers, psychologists, psychiatry team]?
- For patients with existing mental health challenges: Have you noticed that your [depression, anxiety] has gotten worse during this experience? How have you managed that? Who have you spoken to about it?
- To family members: Are there any other symptoms, such as change in mood or spirits, you have observed that we should be aware of?

DOMAIN 4: SOCIAL ASPECTS OF CARE

The social fabric has been significantly stressed throughout the COVID-19 pandemic. Standard in-person communication pathways, support systems, and human connectivity have evaporated as a result of quarantining and isolation. COVID-19 has disproportionately affected people of color, those with low socioeconomic status, and other marginalized and at-risk populations; it is critical to understand individualized social determinants in each healthcare scenario. Social factors include the environments in which people live, work, and play; their access to education, food, health care, medications and treatments, and social care services; and the determinants that directly inform their ability to create, sustain, and nourish their experience of health.

- How is your social support network and community during the COVID-19 pandemic?
- Have you had feelings of isolation during this time? Has it affected your health and well-being?
- Do you have concerns about your social welfare during the pandemic once you are discharged?
- Are you able to fill your prescriptions? Do you have enough medications to manage your physical and psychological symptoms?
- Can we support any of your social needs or concerns (e.g., transportation to visits, education about virtual care, access to technology, insurance issues) that are unmet as a result of the COVID-19 pandemic and having cancer?
- To family members: How can we support you to take care of your loved one's oncology needs?

DOMAIN 5: SPIRITUAL, RELIGIOUS, AND EXISTENTIAL ASPECTS OF CARE

The COVID-19 pandemic has disconnected individuals from their spiritual communities and other networks. Pandemic-related fears and worries have amplified existential anxiety related to death, isolation, and abandonment. Patients may believe there are religious or spiritual explanations for COVID-19 or for their illness (e.g., punishment for sins). Religious leaders who may play integral roles in the serious illness decision-making of their community members may be unavailable or difficult to reach.

- Did your cancer diagnosis affect your faith beliefs, practices, and traditions? How has the COVID-19 pandemic affected these?
- Has the COVID-19 pandemic changed how you find meaning in your life, particularly with a cancer diagnosis? How so?
- How has the importance of religion or faith changed during the COVID-19 pandemic?
- Do you feel supported by your faith community right now?
- Do you have any spiritual concerns or needs related to the COVID-19 pandemic?

DOMAIN 6: CULTURAL ASPECTS OF CARE

Cultural communities and relationships have likely been affected by social isolation associated with COVID-19, potentially leading to feelings of increased fear. Patients with cancer may feel more isolated because of their immunocompromised status. Many cultures prioritize community decision-making over individual autonomy and may be struggling to adapt to visitor restrictions and/or other emerging social norms from the COVID-19 pandemic. Cultural beliefs and practices in the context of serious illness and during the time surrounding death are critical to the bereavement process and the welfare of the patient, family, and cultural community. With a cancer diagnosis, there may have been one set of beliefs. The COVID-19 pandemic may add new and changing beliefs.

- To whom can we speak to about your care? With whom can we share the details of your care?
- How do you make healthcare decisions within your family? Do you make them alone or in consultation with your family or community?
- Who is your support system? Are they aware that you are in the [hospital, clinic]? Would you like us to help you talk with them?
- We want to ensure care is respectful at all times. Is there anything you prefer or that you find problematic that we should know about?
- What name do you prefer we use? What gender do you identify as? What gender pronouns do you use? Whom do you consider to be your family?

DOMAIN 7: CARE OF THE PATIENT NEARING THE END OF LIFE

The COVID-19 pandemic is causing unprecedented mortality rates worldwide, particularly for at-risk patients such as those with cancer. Nurses across healthcare systems and settings are bearing witness to suffering and difficult deaths more frequently than ever before. Maintaining the sanctity imperative to end-of-life care has become increasingly complex in the context of COVID-19, with oncology nurses taking increased responsibility to navigate complex family dynamics at all stages of the bereavement process. The pandemic has required oncology nurses to discuss, address, tend to, and reflect on death and dying in ways that may affect their health and well-being into the future.

- Are you at peace?
- What are you most worried about?
- How do you best like to be comforted?
- To patients and family members: What is most important to you right now? What are you hoping for?
- To family members: This is a difficult time and everyone's needs are different. What information do you need as your loved one nears the end of their life? How can we best support you?

DOMAIN 8: ETHICAL AND LEGAL ASPECTS OF CARE

The COVID-19 pandemic has complicated decision-making in the clinical context, particularly for the most vulnerable patients, including those with cancer. Palliative care philosophy does not endorse the valuation of life or the rationing of resources when avoidable; the goal of palliative care is to optimize quality of life in accordance with the values and preferences of the patient and family and to minimize suffering. Moral suffering of clinicians has been an issue of notable concern —particularly for nurses—as complex ethical decision-making is becoming more prevalent in everyday clinical and oncology nursing practice.

- Do you have a person you have assigned to make decisions for you if you are unable to do so?
- If not, who would you want to make decisions for you in the event that you were unable to make decisions for yourself? Do they know you want them to do this?
- Have you ever thought about getting really sick? Have you thought about how much treatment you would want?
- How can I help you document these wishes?

FIGURE 2. PRIMARY ONCOLOGY NURSING CONCERNS AND QUESTIONS FOR PATIENTS AND FAMILY MEMBERS ACROSS THE DOMAINS OF PALLIATIVE CARE DURING THE COVID-19 PANDEMIC

Note. Based on information from End-of-Life Nursing Education Consortium, 2020b; Hospice and Palliative Nurses Association, 2020; Oncology Nursing Society, 2019.