

PURPOSE



To provide oncology nurses with primary palliative care skills to ensure patient and family-centered care to mitigate suffering and optimize quality of life for the COVID-19 positive adult patient with cancer.

HOW TO USE THIS GUIDE



These recommendations are aligned with the Clinical Practice Guidelines of the National Consensus Project (NCP; 2018) and established palliative nursing competencies to optimize primary palliative care in COVID-19 oncology care.

BACKGROUND

Patients with cancer are especially vulnerable to COVID-19 and are at higher risk for serious COVID-19 related symptoms and rapid physical decline.



WHY ONCOLOGY NURSING?



As oncology nurses, you have the opportunity to ensure the provision of timely, effective, and safe primary palliative care for patients across the lifespan, in all settings, and throughout the care continuum.

PRIMARY PALLIATIVE CARE RESPONSIBILITIES

Primary palliative care may include a number of responsibilities, including:

- Prioritizing pain and symptom management
- Advocating for patient and family unit needs and priorities in the setting of clinical care
- Ensuring streamlined communication between oncology teams and patients/families
- Assessing for coping strategies and needed psychosocial and spiritual services
- Eliciting cultural values and preferences
- Identifying the need for specialist palliative care as needed



SIGNIFICANCE

The cancer trajectory in the setting of COVID-19 becomes increasingly complicated due to several considerations:

- Stage and aggressiveness of cancer
- Adequate resources for cancer care (e.g., personal protective equipment, staff, personnel, medications)
- Side effects of curative and disease modifying treatments
- Severity and management of cancer pain and other symptoms
- Admission for disease progression and symptom exacerbation, increasing COVID-19 risk and related anxiety
- Delaying treatment for fear of COVID-19 transmission
- Disease progression in the setting of overwhelmed healthcare systems and providers
- Increased existential anxiety, spiritual distress, or fear related to COVID-19
- Higher prevalence of family caregiver strain
- Social isolation associated with quarantining or distancing mandates
- Disconnection from support systems and communities impacting quality of life
- Patient loneliness and despair affecting wellbeing due to visitor restrictions
- Dying alone or unsupported by family caregivers, other loved ones, and support systems
- Impaired grieving process due to isolation mandates or decreased access to social workers, mental health clinicians, or chaplains



DOMAINS OF QUALITY PALLIATIVE CARE

Per the NCP's (2018) Clinical Practice Guidelines for Quality Palliative Care:

- Domain 1: Structure and Processes of Care
- Domain 2: Physical Aspects of Care
- Domain 3: Psychological and Psychiatric Aspects of Care
- Domain 4: Social Aspects of Care
- Domain 5: Spiritual, Religious, & Existential Aspects of Care
- Domain 6: Cultural Aspects of Care
- Domain 7: Care of the Patient Nearing the End of Life
- Domain 8: Ethical and Legal Aspects of Care

Effective communication skills are critical to primary palliative nursing. For additional guidance, see ELNEC's Communication Guide During COVID-19 and communication vignettes under the "Communication" tab at aacnnursing.org/ELNEC/COVID-19.



Resource National Consensus Project for Quality Palliative Care. (2018). Clinical practice guidelines for quality palliative care (4th ed.). Richmond, VA: National Coalition for Hospice and Palliative Care.

DESCRIPTION



Per the NCP (2018), palliative care can be integrated into any setting, delivered by all clinicians and supported by palliative specialists who are part of an interdisciplinary team. Palliative care includes a comprehensive assessment and is reliant on family engagement, communication, care coordination, and care continuity across settings.

COVID-19 CONCERNS



- The move toward telemedicine may complicate involvement of specialists and interdisciplinary providers.
- “Family engagement” may look different across family units and settings. For example, technology is playing an increased role in family-provider communication. However, not all families have access to or can afford the necessary technology and may require strategic planning with designated proxies and loved ones.
- Care coordination and continuity will require an interdisciplinary team and constant planning to ensure access to needed and available services within a patient's community

ASSESSMENT CONSIDERATIONS



- Who are the key interdisciplinary providers currently involved in circle of care of the patient and their family?
- Which specialist services or other interdisciplinary providers will likely be needed and what are the current mechanisms for contacting them during COVID-19?
- Has the patient documented a surrogate decision maker on file in the medical record? If not, who will assist the patient to complete the paperwork for determining who can make decisions for them if they cannot?
- What is the best method for contacting family or surrogate decision maker, particularly if visitor restrictions are in place?
- Is the patient currently receiving curative or palliative treatments?

QUESTIONS FOR PATIENT/FAMILY



- What is your understanding of the purpose of this visit and its relationship to hospitalization and/or your current treatment for your cancer?
- What are your concerns related to this hospitalization and/or your current treatment?
- Has COVID-19 raised any other worries or fears in your cancer care that you would like to discuss?
- Many of our providers are working virtually at this time. When would be best for social work, or chaplaincy, and volunteers to contact you and your family?

ADDITIONAL SUGGESTIONS FOR CLINICAL PRACTICE



- Consider starting an email chain of all key interdisciplinary providers of the patient on a health compliant, secured database to ensure rapid communication of concerning clinical status changes and promote timely input of all relevant stakeholders.
- Ensure clinical pathway in place to promote timely communication with consultation teams that may be practicing via telemedicine.

RELATED RESOURCES



- American Society of Clinical Oncology. (2020). General Information about COVID-19 & Cancer. Available at: <https://www.asco.org/asco-coronavirus-resources/care-individuals-cancer-during-covid-19/general-information-about-covid-19>
- Oncology Nursing Society. (2020). COVID-19 Fact Sheet and Implications for Patients with Cancer. Available at: <https://voice.ons.org/news-and-views/covid-19-fact-sheet-and-implications-for-patients-with-cancer>
- VitalTalk. COVID Ready Communication Playbook. Available at: <https://www.vitaltalk.org/guides/covid-19-communication-skills/>

DESCRIPTION



Per the NCP (2018), physical care

- Requires understanding the patient's goals in the context of their broader care and will including relieving symptoms to optimize functional status and quality of life
- Requires a holistic approach (i.e., pharmacological, nonpharmacological, behavioral, etc.) to optimize functional status and quality of life
- Requires collaboration among teams, disciplines, and primary and specialty care providers

COVID-19 CONCERNS



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

ASSESSMENT CONSIDERATIONS



- COVID-19 symptoms may have exacerbated existing symptoms or caused new discomfort to arise acutely and severely in the patient with cancer
- Caregivers may become overwhelmed in the home setting while tending to both cancer or treatment symptoms as well as new challenges related to COVID-19
- Symptom management medications that were once effective may need re-evaluation and discussion among the interdisciplinary team
- As the health system and health providers are overwhelmed due to COVID-19, patients on symptom maintenance therapies may have understandably gone un-noticed

QUESTIONS FOR PATIENT/FAMILY



- Do you have any changes in any of your symptoms at this time? (e.g., might include pain, fatigue, 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?

ADDITIONAL SUGGESTIONS FOR CLINICAL PRACTICE



- Ensure routine pain assessments per your organization's protocol, in addition to before and 30-60 minutes following intervention (e.g., analgesic administration)
- Consult palliative care specialty team upstream either in the community or the acute care setting or at time of diagnosis with COVID-19 to ensure readily available input for complex symptom management

RELATED RESOURCES



- Center to Advance Palliative Care. (2020). Symptom Medications COVID-19 Clinical Resource. Available at: <https://www.aacnursing.org/Portals/42/ELNEC/PDF/symptom-medications-covid-19-clinical-resource.pdf>
- ELNEC. (2020). ELNEC Support for Nurses During COVID – Symptom Management Infographics (under "Symptom Management" tab). Available at: <https://www.aacnursing.org/ELNEC/COVID-19>
- Radbruch L et al. (2020). Recommendations for Symptom Control of Patients with COVID-19 – Briefing Note. Global Palliative Care and Covid-19 Series. Available at: <http://globalpalliativecare.org/covid-19/uploads/briefing-notes/briefing-note-recommendations-for-symptom-control-of-patients-with-covid-19.pdf>

DESCRIPTION

Per the NCP (2018), an interdisciplinary approach to psychological and psychiatric care is critical, including social work assessments across settings and specialist psychological and/or psychiatric care as needed. These aspects of care have several implications in clarifying goals of care, eliciting family involvement, addressing complex family dynamics and conflict, and ensuring appropriate support.



COVID-19 CONCERNS



- Social isolation has exacerbated existing mental health conditions, such as depression and anxiety, requiring ongoing specialist input and ongoing assessment
- Fear, worry, and other distress associated with COVID-19 has sparked new mental health challenges for patients with cancer and their families
- Family dynamics may have become more complex in the context of cumulative loss and grief, social work and chaplaincy may be needed more now than before.
- Mental health support may be required long-term beyond hospitalization; consider a plan upstream in hospitalization to promote continuity and coordination of care at discharge

ASSESSMENT CONSIDERATIONS

- What is this patient's mental health history? Have they consulted with psychology, psychiatry, or social work at this institution in the past?
- Worries, concerns, or feelings about cancer or treatment may have changed or affected new perspectives on life, death, and the meaning of illness in the patient's life
- Consider that in a family-centered model, the mental health and wellbeing of family caregivers is also critical to address in the long-term care of the patient at home



QUESTIONS FOR PATIENT/FAMILY



- We are hearing that COVID-19 is really impacting our patients and their families. Can you tell me about how it is affecting your spirits? How has it affected your sense of wellbeing?
- Have you or 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, etc.]?
- For patients with existing mental health challenges: Have you noticed that your [depression, anxiety, etc.] has gotten worse during this experience? How have you managed that? Who have you spoken to about it?

ADDITIONAL SUGGESTIONS FOR CLINICAL PRACTICE

- Many patients will appreciate the opportunity to address their mental health experience during COVID-19. Continue to normalize and validate their experiences.
- Consider the high mortality rates associated with COVID-19 in marginalized populations; identify grief and bereavement services and support mechanisms for family caregivers in the event this patient dies.



RELATED RESOURCES

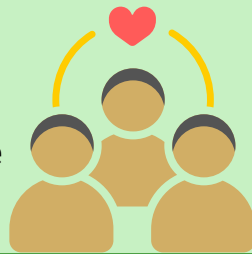


- Oncology Nursing Society. (2020). Psychosocial Support for Patients with Cancer During COVID-19. Available at: <https://voice.ons.org/news-and-views/psychosocial-support-for-patients-with-cancer-during-covid-19>
- Rodin G et al. (2020). The Psychological and Social Implications of physical isolation for Patients and Families During the Coronavirus Pandemic – Briefing Note. Global Palliative Care and Covid-19 Series. Available at: <http://globalpalliativecare.org/covid-19/uploads/briefing-notes/briefing-note-the-psychological-and-social-implications-of-physical-isolation-for-patients-and-families-during-the-coronavirus-pandemic.pdf>

KEYWORDS: SOCIAL DETERMINANTS OF HEALTH; SOCIAL FACTORS; ENVIRONMENTAL FACTORS; SOCIAL FUNCTIONING

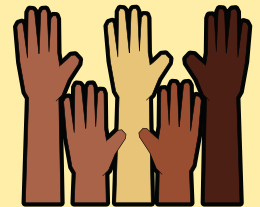
DESCRIPTION

Per the NCP (2018), addressing the social determinants of health that impact patient/family functioning and quality of life is critical. Furthermore, appropriately using interdisciplinary resources allows the team to optimize function and achieve patient/family goals of care.



COVID-19 CONCERNS

- The social fabric has been significantly impacted throughout the COVID-19 pandemic
- “Normal” communication pathways, support systems, and human connectivity has evaporated in the context of quarantining and isolation
- COVID-19 has disproportionately impacted Persons 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, and health and social care services, and the determinants that directly inform their ability to create, sustain, and nourish their experience of health



ASSESSMENT CONSIDERATIONS

- Is there an in-depth social history available for this patient and/or family unit? If so, familiarize yourself with their background to better understand their social factors
- Remember that people living in low-income zip codes may have trouble obtaining certain prescription medication (e.g., opioids), accessing routine healthcare services, and may have safety or wellbeing concerns that extend beyond your understanding
- Social isolation has become heightened throughout the COVID-19 pandemic, impacting physical and social functioning, access to care, and quality of life
- Those experiencing domestic violence or substance abuse may have confronted increased challenges during COVID-19; assess and intervene accordingly



QUESTIONS FOR PATIENT/FAMILY

- Can you tell me about your social support network and community during COVID-19?
- Have you had feelings of isolation during COVID-19? Has it affected your health and wellbeing?
- Do you have concerns about your social welfare during COVID-19 once you are discharged?
- Can we support any of your social needs or concerns that are unmet as a result of COVID-19 and having cancer?



ADDITIONAL SUGGESTIONS FOR CLINICAL PRACTICE

- Social worker involvement is imperative to the broader social welfare of the patient and family; advocate for consultation upstream in the continuum as appropriate
- Ascertain a clear understanding of the patient’s current and desired social functioning to help them best achieve their goals now and upon discharge
- Involve family caregivers and other social support members in social history taking as appropriate and whenever possible with the permission of the patient



RELATED RESOURCES

- American Hospital Association. (2020). Awareness of Social Needs Can Help Address Health Inequity during COVID-19 (Issue Brief). Available at: <https://www.aha.org/system/files/media/file/2020/04/awareness-of-social-needs-can-help-address-health-inequity-during-covid-19.pdf>
- Rodin G et al. (2020). The Psychological and Social Implications of physical isolation for Patients and Families During the Coronavirus Pandemic – Briefing Note. Global Palliative Care and Covid-19 Series. Available at: <http://globalpalliativecare.org/covid-19/uploads/briefing-notes/briefing-note-the-psychological-and-social-implications-of-physical-isolation-for-patients-and-families-during-the-coronavirus-pandemic.pdf>

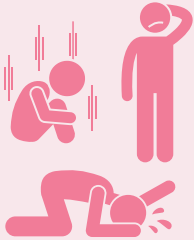


DESCRIPTION

Per the NCP (2018), the spiritual beliefs, practices, values, and traditions of all patients should be respected and integrated into care across the continuum. Similarly, the team should respect the right of patients to decline spiritual care or discuss their beliefs in detail.



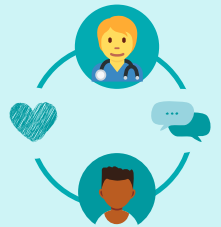
COVID-19 CONCERNS



- COVID-19 has disconnected individuals from their spiritual communities and other networks
- COVID-19 associated fears and worries have amplified existential anxiety related to death, isolation, and abandonment for individuals with cancer
- Patients may believe there are religious explanations for COVID-19, as well as for their cancer diagnosis (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 – plan ahead

ASSESSMENT CONSIDERATIONS

- While COVID-19 may have disrupted cancer treatment plans and normal social functioning, it may have also affected fundamental spiritual beliefs, values, traditions, and practices
- It is critical to understand both the value of religious and/or spiritual aspects of care to the patient/family and how they understand the purpose and meaning of illness and suffering
- People who have cancer and now confront COVID-19 may be experiencing fear related to the end of life; this distress should be assessed and supported to throughout the care trajectory
- Spiritual reflection may lead patients who previously declined or avoided end of life care or comfort-focused care plan options to initiate such discussions; be prepared to welcome the conversation



QUESTIONS FOR PATIENT/FAMILY

- How has the importance of religion or faith changed during COVID-19?
- Has COVID-19 changed how you find meaning in your life? How so?
- How has the importance of spiritual concerns, religion, or faith changed during COVID-19?



- Do you feel supported by your faith community right now?
- Are there any spiritual concerns or needs that have arisen out of COVID-19 that are important for us to know about?
- Is it okay if we continue to attend to your spiritual care needs?

ADDITIONAL SUGGESTIONS FOR CLINICAL PRACTICE



- The clinical course for COVID-19 positive patients is unpredictable; ensure clear documentation of spiritual beliefs and needs and ensure clear communication pathways to spiritual leaders, chaplains and palliative care specialists to promote timely resources
- Does your organization have a protocol in place to obtain 'final blessings' at the time of death from various spiritual leaders via virtual technology or phone? Plan a protocol or guideline based on available technology
- Ensure a spiritual care plan to meet needs of patients/families and communities as needed

RELATED RESOURCES

- Ferrell BR et al. (2020). The urgency of spiritual care: COVID-19 and the critical need for whole-person palliation (includes spiritual assessment). J Pain Symptom Manage. Epub ahead of print. Available at: [https://www.jpmsjournal.com/article/S0885-3924\(20\)30578-9/fulltext](https://www.jpmsjournal.com/article/S0885-3924(20)30578-9/fulltext)
- Puchalski C et al. (2020). Interprofessional Spiritual Care in the Time of COVID-19 – Briefing Note. Global Palliative Care and Covid-19 Series. Available at: <http://globalpalliativecare.org/covid-19/uploads/briefing-notes/briefing-note-interprofessional-spiritual-care-in-the-time-of-covid-19.pdf>



DESCRIPTION

Per the NCP (2018), it is imperative for healthcare providers to reflect upon personal biases related to race, ethnicity, gender identity, gender expression, sexual orientation, immigration and refugee status, social class, religion, spirituality, physical appearance, and abilities. Honoring and respecting cultural values and integrating them into culturally sensitive care should be prioritized for all patients.



ASSESSMENT CONSIDERATIONS

- Many disenfranchised persons may identify with communities and families of choice rather than families of origin due to discrimination, violence, or other abusive behaviors (e.g., the literature notes several instances among LGBTQ+ persons and persons experiencing homelessness)
- Understanding cultural beliefs and practices is critical to understanding how the patient and family make meaning of health, illness, death, their cancer diagnosis, and current condition
- There may be various subcultures within a certain culture “label”; person-centered care invites oncology nurses to individualize care regardless of cultural affiliations with awareness of personal assumptions and biases about cultural groups



COVID-19 CONCERNS

- “Culture” may encompass the beliefs, practices, traditions, and/or values of various racial and ethnic groups, religions and faith traditions, differing levels of ability, sexual and gender minorities, and social classes among others
- Cultural communities and relationships have likely been impacted due to social isolation associated with COVID-19, potentially leading to feelings of increased fear
- Many cultures prioritize community, decision-making and togetherness over individual autonomy; It may be hard to adapt to visitor restrictions and COVID-19 related practices
- Cultural beliefs and practices in the context of serious illness and during the time surrounding death are critical to the bereavement process and welfare of the patient, family, and cultural community



QUESTIONS FOR PATIENT/FAMILY

- With 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 family or community?
- Who is your support system? Are they aware you are in the hospital? Would you like us to help you talk to them?
- 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?



ADDITIONAL SUGGESTIONS FOR CLINICAL PRACTICE

- Cultural considerations vary significantly among persons and populations; anticipate cultural care needs throughout the continuum of care
- Upon initial assessment, identify pathways to ensure culturally appropriate communication through the use of interpreters, cultural communities, family members, and other stakeholders



RELATED RESOURCES

- Quality Interactions. (2020). Cross-Cultural Care and Communication During COVID-19. Available at: <https://www.youtube.com/watch?v=OkoNufo5nb8>
- Rosa WR et al. (2020). LGBTQ+ inclusive palliative care in the context of COVID-19: Pragmatic recommendations for clinicians. J Pain Symptom Manage. Epub ahead of print. Available at: [https://www.jpmsjournal.com/article/S0885-3924\(20\)30373-0/fulltext](https://www.jpmsjournal.com/article/S0885-3924(20)30373-0/fulltext)



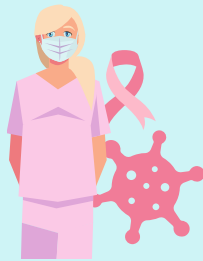
DESCRIPTION



Per the NCP (2018) guidelines, attention to all domains of care becomes increasingly important at the time an individual nears death. Hospice care is the gold standard for patients nearing the end of life and should be introduced early so individuals/families understand its philosophy, eligibility, benefits, and limitations.

COVID-19 CONCERNS

- COVID-19 is causing unprecedented mortality rates worldwide, particularly for patients immunocompromised from cancer
- Nurses across systems and settings are bearing witness to increased suffering and greater numbers of deaths than ever before
- Maintaining the sacredness imperative to end-of-life care has become increasingly challenging in the context of COVID-19, with oncology nurses taking greater responsibility to navigate complex family dynamics at all stages of the bereavement process
- COVID-19 has required oncology nurses to discuss, address, tend to, and reflect on death and dying in ways that may impact nurses' health and wellbeing into the future



ASSESSMENT CONSIDERATIONS



- Individuals with cancer who are diagnosed with COVID-19 may experience rapid physical decline, leaving them emotionally, spiritually, mentally, or socially unprepared to die
- Social and caregiver considerations should be prioritized in the context of changing visitor restrictions and the need for loved ones to have closure to say good-bye and provide comfort at bedside
- Assessing spiritual and cultural needs throughout the cancer trajectory will assist with streamlining care to ensure integrity and the end of life
- Marginalized or isolated individuals often require additional emotional support at this time

QUESTIONS FOR PATIENT

- Are you at peace?
- What are you most worried about?
- How do you best like to be comforted?



QUESTIONS FOR PATIENT AND FAMILY

- What is most important to you right now?
- What are you hoping for?
- This is a difficult time and everyone's needs are different. Can you tell me a little about how you think the team and I can best support you?

ADDITIONAL SUGGESTIONS FOR CLINICAL PRACTICE

- The time surrounding death remains sacred ground despite changes secondary to COVID-19
- Maintain exemplary practices related to delivery of compassionate care, creating a healing and therapeutic environment, using deep listening, and validating the patient/family experience
- Prioritize self-care and emotional processing as cumulative exposure to serious illness, dying, and death affects nurses' wellbeing over time



RELATED RESOURCES



- Anewalt P et al. (2020). Grief and Bereavement for Family Members who Can't Visit their Sick Relatives or Attend Funeral Services– Briefing Note. Global Palliative Care and Covid-19 Series. Available at: <http://globalpalliativecare.org/covid-19/uploads/briefing-notes/briefing-note-grief-and-bereavement-for-family-members-who-cant-visit-their-sick-relatives-or-attend-funeral-services.pdf>
- Hospice & Palliative Nurses Association. (2020). HPNA Primary Palliative Nursing for Patients with COVID-19: Nursing Care and Support at the End of Life. Available at: https://advancingexpertcare.org/HPNAweb/Education/COVID19_PrimaryPalliativeNursing.aspx

DESCRIPTION

Per the NCP (2018), ethical principles apply to the care of all patients, as well as the legalities related to decisions by healthcare proxies and surrogate decision-makers. Familiarity with laws regarding nursing scope of practice, advance care planning, decisions about life-sustaining treatments, and treatments with legal considerations, such as medical cannabis, is necessary.



COVID-19 CONCERNS

- COVID-19 has complicated decision-making in the clinical context, particularly for individuals who are clinically vulnerable, including those with a diagnosis of cancer
- Palliative care philosophy does not endorse the valuation of life nor the avoidable rationing of resources; the goal of all palliative care is to optimize quality of life and minimize serious health-related suffering in accordance with individual and family values and preferences
- Moral suffering of clinicians is a significant concern – particularly for nurses – due to the prevalence of daily complex ethical decision-making in clinical practice at the bedside



ASSESSMENT CONSIDERATIONS

- Family and support system structures have changed during COVID-19; if there is advance care planning documentation, ensure it is up-to-date and reflects the patient's current preferences
 - Maintain current familiarity with your health organization's legal and ethical implications of policies in response to COVID-19 management
 - Ensure communication pathways to vital leadership in challenging clinical scenarios
- COVID-19 has illuminated ethical nuances and priorities; ethical dilemmas cannot always be settled with a discussion of the basic bioethical preferences (e.g., autonomy, beneficence, nonmaleficence, justice) but rather requires an in-depth assessment of ethical values and perspectives from the patient/family perspective



QUESTIONS FOR PATIENT/FAMILY

- 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?
- How can I help you document your health care wishes?
- We routinely ask all patients this question as part of their health care. In the event that your lungs were to stop working normally, would it be acceptable to place you on a breathing machine while we continue to try and fix the problem?



ADDITIONAL SUGGESTIONS FOR CLINICAL PRACTICE

- Ensure ready access to or initiate a communication pathway to ensure continued involvement of a clinical ethics committee to assist in challenging clinical scenarios
- Develop transparent nurse and interdisciplinary communication mechanisms to convey moral distress in a timely manner
- Identify opportunities to advance nursing presence on clinical ethics teams or initiate a nurse-led ethics team to address practice challenges during COVID-19 in the oncology setting



RELATED RESOURCES

- Ciruzzi S et al. (2020). Bio-Ethical Principles, Practices, and Recommendations Relevant to the COVID-19 Pandemic – Briefing Note. Global Palliative Care and Covid-19 Series. Available at: <http://globalpalliativecare.org/covid-19/uploads/briefing-notes/briefing-note-bio-ethical-principles-practices-and-recommendations-relevant-to-the-covid-19-pandemic.pdf>
- Mazanec P. COVID-19 Resource: Ethical dilemmas facing nurses during the Coronavirus Crisis: Addressing moral distress. Available at: <https://sigma.nursingrepository.org/handle/10755/20413>

The nature of suffering is highly individualized and defined by a person's meaning of a situation that "threaten[s] the intactness of the person as a complex social and psychologic entity" (Cassell, 1982). Oncology nurses witness and shoulder a profound amount of suffering in the routine delivery of care. The experience of suffering during COVID-19 has been exacerbated by many of the issues previously discussed in these infographics. Suffering, for individuals with cancer and oncology nurses, can be relieved by addressing the eight domains of care strategically, regularly, and with a commitment to primary palliative nursing.

Oncology nurses confronting the suffering of individuals with cancer and colleagues, as well as their own suffering, may find it helpful to reflect on the goals of their nursing practice and service. Certain tenets identified by Ferrell & Coyle (2008 pp. 108-9) may assist with guiding the integrity of nursing practice during the COVID-19 era and beyond in attending to the experience of suffering.

- 1 Suffering can be understood as a loss of control, leading to insecurity. People who are suffering often feel helpless and trapped, without escape from current circumstances. This is particularly true with COVID-19 since patients and nurses are living and working in COVID-19 without respite.
 - Oncology nurses must assess for suffering in patients with cancer including social isolation and fear of contracting COVID-19.
- 2 Suffering is often associated with loss (e.g., loss of socialization due to necessity of social distancing, loss of a physical interaction, loss of routine due to immunocompromise, loss of future, loss of physical abilities due to reduced care delivery). Whether the loss is outwardly apparent or only in the experience of the person who is suffering, it can contribute to feelings of diminishment and brokenness.
 - Oncology nurses must assess patients with cancer for these losses and the additional losses and psychosocial suffering secondary to COVID-19.
- 3 Suffering is intensely personal and has increased for patients with cancer in the COVID 19 pandemic who are worried about their cancer, their cancer treatment, and the potential for their increased of exposure and developing COVID-19.
 - Oncology nurses must individualize assessment to patients and family needs and discuss suffering with cancer care and COVID-19.
- 4 Intense emotions may accompany suffering (e.g., sadness, fear, abandonment, etc.)
 - Oncology nurses must assess for these intense symptoms, normalize and validate patients' experiences, use therapeutic communication techniques, including active listening, and bring in appropriate interdisciplinary team members.
- 5 Recognition of one's mortality and fear of death may be closely related to suffering. Some individuals may desire death when faced with the alternative of serious illness. Considering one's potential demise by cancer and COVID 19 may be overwhelming.
 - Oncology nurses must make time to attend to the suffering and existential anxiety that has become pronounced by COVID-19, providing patients and families with tools for resilience and coping.
- 6 The question "Why?" often pervades the experience of suffering. Often, meaning and answers that are unknowable are often sought. They may be magnified for individuals who are already suffering from cancer and must also be faced with questions of the how and why of COVID-19.
 - Oncology nurses must provide compassionate listening to oncology patients and bring in appropriate interdisciplinary team members. The importance of empathically bearing witness to the patient and family experience cannot be understated.
- 7 Persons who suffer may already feel separated from the world, may express deep loneliness and yearn for connection, while others may be distressed by their dependence on others. In the COVID-19 era, this isolation and distance may be magnified by the need for staff wearing personal protective equipment, social distancing and reduced staff in the room.
 - Oncology nurses must promote interpersonal connection in spite of COVID-19 through expert communication using presence, listening, verbal, and non-verbal communication.
- 8 Hopelessness and spiritual distress are common. Self-evaluation and the relationship to a higher power in the face of one's mortality may be a part of suffering. Chaplaincy may be necessary for patients in the hospital more than ever.
 - Oncology nurses must assess for hopelessness and spiritual distress, provide spiritual care support, and consult with specialist spiritual caregivers as needed.
- 9 Suffering and pain are not synonymous but are closely related. Physical pain is often connected to psychological, social, and/or spiritual pain. Persistent pain in the absence of meaning becomes suffering.
 - Oncology nurses must use the nursing process to assess for total pain and collaborate with interdisciplinary partners to address it.
- 10 When a person feels they do not have a voice, suffering occurs. The sufferer may be unable to give words to their experience or they may be confronting unheard "screams" from within.
 - Oncology nurses must assure the patient has a voice in the design, implementation, and evaluation of their care.

Thank you for the sacred and profound work of oncology nursing during this pandemic! We honor and salute you.