

■ Article

# Working Together: Including Palliative Care With Oncology Care

Mary Kazanowski, PhD, APRN, BC, ACHPN®, and Lisa Kennedy Sheldon, PhD, APRN, BC, AOCNP®



© Catherine Yeulet/iStock/Thinkstock

Standards released by the American College of Surgeons Commission on Cancer program in 2012 call for all patients with cancer to have access to palliative care and for institutions to provide skilled and coordinated care as patients traverse through multiple healthcare settings. Many healthcare providers do not understand what palliative care can provide, or how it differs from hospice or end-of-life care. Oncology nurses and advanced practice nurses play an important role in educating healthcare providers, patients, and families about the role of palliative care and implementing it in the care of patients with cancer.

Mary Kazanowski, PhD, APRN, BC, ACHPN®, is a hospice and palliative care nurse practitioner at Visiting Nurse Association Hospice of Manchester and Southern NH in Manchester, NH, and an advanced practice nurse on the palliative care team at Concord Hospital in Concord, NH; and Lisa Kennedy Sheldon, PhD, APRN, BC, AOCNP®, is an assistant professor in the College of Nursing and Health Sciences at the University of Massachusetts–Boston. The authors take full responsibility for the content of the article. The authors did not receive honoraria for this work. The content of this article has been reviewed by independent peer reviewers to ensure that it is balanced, objective, and free from commercial bias. No financial relationships relevant to the content of this article have been disclosed by the authors, planners, independent peer reviewers, or editorial staff. Kazanowski can be reached at [mkaz.nh.ultranet@rcn.com](mailto:mkaz.nh.ultranet@rcn.com), with copy to editor at [CJONEditor@ons.org](mailto:CJONEditor@ons.org). (Submitted September 2013. Accepted for publication September 15, 2013.)

Key words: cancer program development/evaluation; palliative care; quality of life; standards and guidelines

Digital Object Identifier: 10.1188/14.CJON.S1.45-48

One of the major problems in the healthcare system is fragmentation, with different providers overseeing one organ system or disease process. Individuals may receive care from several healthcare providers in multiple settings in the community, including acute care, home care, and ambulatory care. With good communication among providers, this system can and should meet the needs of each and every patient; however, the opportunity for a quality outcome is missed if the patients and providers lack all necessary information to make decisions, and if patient needs are not identified.

Palliative care is a healthcare specialty increasingly being used to bridge the gaps in patient care that occur across and within healthcare settings. Once considered a type of care reserved for those with a terminal illness, palliative care now is recognized as a service that provides individuals with a serious illness an opportunity to look at the whole picture and review their healthcare status and needs earlier in their disease process. That “whole picture” includes available information about the expected trajectory of disease, prognosis, treatment options, and the benefits and side effects of treatment. With palliative care, time is allotted for individuals and their family members to ask questions and convey concerns in an effort to identify issues that impact the illness experience. In addition,

individuals are encouraged to identify their goals of care, which should guide them in decision making. Encouraging patient and family participation facilitates shared decision making about treatment consistent with their goals and values.

Palliative care also is a service that deals with the assessment and treatment of symptoms related to disease, treatment, or acquired syndromes that may develop during the trajectory of an illness. Symptoms may be physical or psychological in nature, often imbedded with emotional, spiritual, or existential aspects of one's life experience. Symptoms include, but are not limited to, fatigue, weakness, insomnia, anxiety, fear, depression, pain, nausea, vomiting, and constipation (Goldstein & Morrison, 2013). The evidence base for palliative treatment of symptoms has increased along with the growth of the discipline (Goldstein & Morrison, 2013). Consequently, better options now exist for treatment of common symptoms such as pain, nausea, constipation, and delirium. In addition, the palliative literature is rich in new approaches to symptoms management, which now are available to more patients through formal palliative consultations and informal sharing of knowledge among providers.

What makes palliative care different from end-of-life care is its timing in the illness trajectory. Unlike end-of-life care, palliative care can be provided concomitantly with aggressive and even

## Case Study

Ms. S is a 55-year-old single mother with two teenage children and works as a licensed nursing assistant on the 3–11 pm shift at a local skilled nursing facility. She was treated for breast cancer five years ago but recently diagnosed with a recurrence. She is planning to start second-line chemotherapy.

During her first meeting with the oncology nurse, Ms. S has questions about what lies ahead and states she has difficulty making decisions. She is having difficulty sleeping and states that she feels depressed. In previous visits with her oncologist, Ms. S mentioned some of these concerns and the oncologist referred her to her primary care provider (PCP). The oncology nurse asked the PCP about setting up a consultation by the palliative care team for Ms. S. The PCP responds that Ms. S is not “end stage,” and he does not want her to “give up hope.” How should the nurse respond?

curative treatment for an illness (Quill et al., 2010). Palliative also differs from other types of care because it is interdisciplinary, addressing psychosocial, cultural, and spiritual concerns of patients and their families (National Consensus Project for Quality Palliative Care, 2009). Healthcare providers and patients and their families significantly misunderstand what palliative care is and what role it plays for patients with serious illness. That often occurs because of its roots in the hospice movement (Meier, 2006). Palliative care, as an entity separate from hospice, evolved to meet the needs of the growing numbers of patients with chronic disease (Brunnhuber, Nash, Meier, Weissman, & Woodcock, 2008). The model in Figure 1 illustrates how palliative care currently fits in the course of serious illness.

Unlike end-of-life care or hospice (a program of care), palliative care is implemented when a provider (physician or advanced practice registered nurse [APRN]) refers patients to a palliative care provider who conducts consultations and follow-up visits, often meeting with patients and families and contacting multiple providers involved in the patient's care. As of 2009, palliative care services were available in 80% of hospitals with more than 300 beds, and 60% of hospitals with 50 or more beds (Grant, Elk, Ferrell, Morrison, & von Gunten, 2009). Palliative care consultations also are provided on an outpatient basis; in clinics, physician offices, and patient homes; or in the long-term care setting. Various models with different providers exist, depending on the needs of a community and available resources. Consultations generally are conducted by physicians or nurse practitioners who have completed fellowships in palliative care and, ideally, have been certified in this specialty. Physicians are certified by the American Academy of Hospice and Palliative Medicine; nurse practitioners are certified by examination by the National Board for Certification of Hospice and Palliative Nurses. Physicians and nurse practitioners also work closely (sometimes as a “palliative team”) with members of other disciplines, including counselors, spiritual care providers, medical social workers, pharmacists, or nurses, who all provide their expertise in identifying particular problems and facilitating patient needs.

The goal of palliative care is to improve quality of life for patients and their families (Goldstein & Morrison, 2013). Studies have shown that quality of life is better (i.e., improvement in symptoms, mood, and end-of-life care) for patients who receive palliative care in addition to their usual care (Bakitas et al., 2009;

Follwell et al., 2009). A landmark study by Temel et al. (2010) demonstrated that patients with cancer who received palliative care in addition to their usual cancer care had longer survival than those without palliative care. The positive impact that palliative care has on the cancer experience has led to the development of standards of care that specifically call for the inclusion of palliative care for patients with cancer (Goldstein & Morrison, 2013).

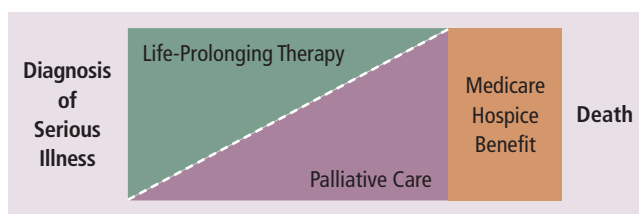
## Oncology and Palliative Care

Since the 1960s, significant improvement has been made in the care and outcomes for people with cancer (American College of Surgeons [ACOS], 2012). Despite that, the Institute of Medicine ([IOM], 1999) released a report on the state of cancer care in the United States that said substantial evidence shows that many patients with cancer do not receive the benefits of high quality care. In response to the IOM report, the ACOS Commission on Cancer (CoC) made a number of key recommendations and developed standards outlined in the document *Cancer Program Standards 2012: Ensuring Patient-Centered Care*. The document ensured that “each cancer program seeking accreditation provides all patients with a full range of diagnostic, treatment, and supportive services either on-site at the facility or by referral to another location, including community-based resources” (ACOS, 2012, p. 15).

The CoC is a consortium of professional organizations dedicated to improving survival and quality of life for patients with cancer. One way it accomplishes this is by establishing standards for cancer programs and evaluating and accrediting programs according to those standards. As of 2012, it was the accreditation body for more than 1,500 cancer programs in the United States and Puerto Rico, representing 30% of all hospitals that provide care to more than 70% of newly diagnosed patients with cancer annually (ACOS, 2012).

With regard to palliative care, the CoC standards state that palliative care services are available to patients either on-site or by referral. That particular standard (2.4) requires that services be provided by an interdisciplinary team of medical staff, mental health professionals, social workers, and spiritual counselors, and that they be available (a) at the time of diagnosis, (b) throughout treatment, (c) during surveillance and, when applicable, (d) during bereavement (ACOS, 2012).

Standard 2.4 also addresses the role of nurses in providing palliative care as part of an off-site referral team. A physician is required for an off-site team, but a nurse also may be a member of this team. The CoC standard strongly encourages that the



**FIGURE 1. Palliative Care's Place in the Course of Illness**

Note. From *Clinical Practice Guidelines for Quality Palliative Care* (2nd ed., p. 6), by the National Consensus Project for Quality Palliative Care, 2009, Pittsburgh, PA: Author. Copyright 2009 by National Consensus Project for Quality Palliative Care. Reprinted with permission.

For a nurse practitioner to achieve certification in palliative care, one must meet eligibility criteria to sit for the Certification Examination for the Hospice and Palliative Advanced Practice Registered Nurses, by having one of the following:

- Master's or higher degree in nursing from an advanced practice palliative care accredited education program providing both a didactic component and a minimum of 500 hours of supervised advanced practice specifically in palliative care in the year prior to applying to take the examination, or
- Post-master's certificate in nursing with a minimum of 500 hours of supervised advanced clinical practice specifically in palliative care in the year prior to applying to take the examination, or
- Master's, post-master's, or higher degree in nursing from an advanced practice program as a nurse practitioner with 500 hours of post-master's advanced practice in providing palliative care (direct and/or indirect) in the year prior to applying to take the examination.

Candidates achieving a passing score on this examination are awarded the Advanced Certified Hospice and Palliative Nurse (ACHPN®) credential.

## FIGURE 2. Nurse Practitioner and RN Certification in Palliative Care

*Note.* From ACHPN® Candidate Handbook (p. 9), by the National Board for Certification of Hospice and Palliative Nurses, 2014. Retrieved 1/1/2014 from <http://www.nbchpn.org/DisplayPage.aspx?Title=Candidate%20Handbooks/Applications>. Copyright 2014 by National Board for Certification of Hospice and Palliative Nurses. Reprinted with permission.

nurse on the palliative referral service have specialized training or certification in hospice and palliative care (see Figure 2).

Policy and guidelines from other professional organizations also support the integration of oncology and palliative care. The American Society of Clinical Oncology vision of personalized medicine stated that patient preferences and goals should be addressed to help direct discussions regarding treatment options (Peppercorn et al., 2011). The National Comprehensive Cancer Network Clinical Practice Guidelines in Oncology also integrate palliative care with the treatment for cancer (Levy et al., 2009); their palliative care guidelines are accessible at [www.nccn.org/professionals/physician\\_gls/pdf/palliative.pdf](http://www.nccn.org/professionals/physician_gls/pdf/palliative.pdf).

## Palliative Care and Oncology

By virtue of their work with patients with malignant disease, oncology nurses and oncologists have vast amounts of knowledge and experience in symptom management. Oncology nurses provide key components of palliative care (Ramchandran & von Roenn, 2013). However, other components of palliative care are best addressed by a multidisciplinary approach, including communication around the meaning and impact of advanced illness in a physical, social, and spiritual context, as well as transitions to care (e.g., anticancer therapy to hospice care). Information about prognosis is best provided by an oncologist, but research shows that only about a third of oncologists give patients their prognosis (Kiely, Stockler, & Tattersall, 2011); and oncologists also are not likely to have early discussions about end-of-life issues. Although some patients may not want this information, truthful education is needed to make informed decisions about treatment throughout the illness trajectory (Smith & Longo, 2012). In addition, truthful and sensitive conversations

that acknowledge death help patients understand whether they can be cured, are welcomed by patients, and do not take away hope or cause depression (Mack & Smith, 2012).

If oncologists have difficulty initiating conversations about prognostic data or end-of-life issues, a consultation to a palliative provider or team is appropriate. Patients with cancer with complex palliative issues would benefit from the added skills that palliative care specialists from various disciplines provide. These include counselors, chaplains, pharmacists, and social workers with knowledge of palliative issues, including options for care and how patients can access them.

## Case Study Review

In the case study, Ms. S now has concerns about the trajectory of her disease. She has begun to have difficulty making decisions and is experiencing symptoms of distress (i.e., difficulty sleeping and feelings of depression). Each of those issues can negatively impact her quality of life and should be addressed in a timely manner. The primary care provider's (PCP's) statement that Ms. S is not end-stage reflects a misunderstanding of what palliative care does, when it should be instituted, and what it does not do (e.g., take away hope). How each issue is addressed will depend on the PCP's comfort level and expertise with these issues, as well as the PCP's understanding of Ms. S's goals of care. Given the multiple issues and the possibility that her disease trajectory will be long and complex, a palliative consultation is appropriate and, possibly, essential to meet the patient's needs.

The perception that palliative care means end-of-life care is commonly held by healthcare providers and the public. Education and skilled communication may be useful in addressing that misconception. For example, in response to the PCP's statement that he did not want to take away Ms. S's hope, the nurse informed the PCP that research shows that providing information to patients with serious illnesses helps them make decisions and can improve their quality of life. In addition, information gives them more control over their response to the illness and facilitates the planning of their lives. Palliative care consultants are available to speak with the oncologist as well as the patient and the family. These conversations can be empowering. Ms. S should remain hopeful for a good outcome, while accessing all the information she needs to make informed decisions. The nurse carefully addressed the goals of palliative care within the context of incorporating the patient in decision making. The oncology nurse also can request an assessment of Ms. S's problems with sleep and depression by the palliative consultant or team. Until those symptoms are better managed, Ms. S will have limited ability to manage the other aspects of her illness.

## Implications for Practice

- ▶ Describe palliative care as integral to the care of patients with cancer and their families.
- ▶ Introduce palliative care to all patients with cancer at the time of diagnosis.
- ▶ Facilitate ongoing access to palliative care for patients and their families throughout the trajectory of their illness.

## Conclusion

Oncology nurses are integral members of the cancer care team. In addition, they serve as patient advocates to encourage the integration of palliative care into oncology care as early in the disease trajectory as needed. Palliative care provides relief from suffering through excellent symptom management and improves overall quality of life (Bakitas et al., 2009; Temel et al., 2010). Offering palliative care is part of providing patients with the highest-quality oncology care and should be a part of all cancer care programs.

## References

- American College of Surgeons. (2012). *Cancer program standards 2012: Ensuring patient-centered care*. Retrieved from <http://www.facs.org/cancer/coc/programstandards2012.pdf>
- Bakitas, M., Lyons, K.D., Hegel, M.T., Balan, S., Brokaw, F.C., Seville, J., . . . Ahles, T. (2009). Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: The Project ENABLE II randomized controlled trial. *JAMA*, 302, 741-749. doi:10.1001/jama.2009.1198
- Brunnhuber, K., Nash, S., Meier, D.E., Weissman, D.E., & Woodcock, J. (2008). *Putting evidence into practice: Palliative care*. London, England: BMJ Group.
- Follwell, M., Burman, D., Le, L.W., Wakimoto, K., Seccareccia, D., Bryson, J., . . . Zimmermann, C. (2009). Phase II study of an outpatient palliative care intervention in patients with metastatic cancer. *Journal of Clinical Oncology*, 27, 206-213. doi:10.1200/JCO.2008.17.7568
- Goldstein, N.E., & Morrison, R.S. (2013). *Evidence-based practice of palliative medicine*. Philadelphia, PA: Saunders.
- Grant, M., Elk, R., Ferrell, B., Morrison, R.S., & von Gunten, C.F. (2009). Current status of palliative care—Clinical implementation, education, and research. *CA: A Cancer Journal for Clinicians*, 59, 327-335.
- Institute of Medicine. (1999). *Ensuring quality cancer care*. Washington, DC: National Academies Press.
- Kiely, B.E., Stockler, M.R., & Tattersall, M.H. (2011). Thinking and talking about life expectancy in incurable cancer. *Seminars in Oncology*, 38, 380-385. doi:10.1053/j.seminoncol.2011.03.007
- Levy, M.H., Back, A., Benedetti, C., Billings, J.A., Block, S., Boston, B., . . . Weinstein, S.M. (2009). NCCN Clinical Practice Guidelines in Oncology: Palliative care. *Journal National Comprehensive Cancer Network*, 7, 436-473.
- Mack, J.W., & Smith, T. (2012). Reasons why physicians do not have discussions about poor prognosis, why it matters, and what can be improved. *Journal of Clinical Oncology*, 30, 2715-2717. doi:10.1200/JCO.2012.42.4564
- Meier, D.E. (2006). Palliative care in hospitals. *Journal of Hospital Medicine*, 1(1), 21-28.
- National Consensus Project for Quality Palliative Care. (2009). *Clinical practice guidelines for quality palliative care* (2nd ed.). Pittsburgh, PA: Author.
- Peppercorn, J.M., Smith, T.J., Helft, P.R., Debono, D.J., Berry, S.R., Wollins, D.S., . . . Schnipper, L.E. (2011). American Society of Clinical Oncology statement: Toward individualized care for patients with advanced cancer. *Journal of Clinical Oncology*, 29, 755-760. doi:10.1200/JCO.2010.33.1744
- Quill, T.E., Holloway, R.G., Shah, M.S., Caprio, T.V., Olden, A.M., & Storey, C.P. (2010). *Primer of palliative care* (5th ed.). Glenview, IL: American Academy of Hospice and Palliative Medicine.
- Ramchandran, K.A., & von Roenn, J.H. (2013). What is the role for palliative care in patients with advanced cancer? In N.E. Goldstein, & R.S. Morrison (Eds.), *Evidence-based practice of palliative medicine*. Philadelphia, PA: Saunders.
- Smith, T.J., & Longo, D.L. (2012). Talking with patients about dying. *New England Journal of Medicine*, 367, 1651-1652. doi:10.1056/NEJMe1211160
- Temel, J.S., Greer, J.A., Muzikansky, A., Gallagher, E.R., Admane, S., Jackson, V.A., . . . Lynch, T.J. (2010). Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine*, 363, 733-742. doi:10.1056/NEJMoa1000678