Abstract
While there are operational, financial, and workforce barriers to integrating oncology with palliative care, part of the problem lies in ourselves, not in our systems. First, there is oncologists’ “learned helplessness” from years of practice without effective medications to manage symptoms or training in how to handle the tough communication challenges every oncologist faces. Unless they and the fellows they train have had the opportunity to work with a palliative care team, they are unlikely to be fully aware of what palliative care has to offer to their patients at the time of diagnosis, during active therapy, or after developing advanced disease, or may believe that, “I already do that.” The second barrier to better integration is the compassion fatigue many oncologists develop from caring for so many years for patients who, despite the oncologists’ best efforts, suffer and die. The cumulative grief oncologists experience may go unnamed and unacknowledged, contributing to this compassion fatigue and burnout, both of which inhibit the integration of oncology and palliative care. Solutions include training fellows and practicing oncologists in palliative care skills (eg, in symptom management, psychological disorders, communication), preventing and treating compassion fatigue, and enhancing collaboration with palliative care specialists in caring for patients with refractory distress at any stage of disease. As more oncologists develop these skills, process their grief, and recognize the breadth of additional expertise offered by their palliative care colleagues, palliative care will become integrated into comprehensive cancer care. (JNCCN 2012;10:1192–1198)

Palliative care is “…an active and systematic approach to addressing issues that are important to patients and families in the setting of serious illness…aimed at yielding improvements in quality of life and relief of suffering. It is focused on optimizing people's function and comfort in the shadow of a limited life expectancy in all of the domains that make us who we are: physical, emotional, spiritual, sexual, social and financial.”

Palliative care is not confined to care at the end of life—that is hospice care. Palliative care is appropriate for all patients with cancer, from diagnosis forward. The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) for Palliative Care and the ASCO vision for 2020 both recommend early consults for selected patients. And for patients with advanced disease, benefits of early referral may include prolongation of life, less depression, and improvement in quality of life, as shown in patients with advanced lung cancer.

Oncology and palliative care should, therefore, be natural partners, but although “supportive care” has been adopted readily, palliative care has not. Recent publications on the financial, operational, and systemic barriers and workforce limitations regarding successful early integration of palliative care or hospice programs into the care of oncology patients describe several model systems that have overcome these barriers. This article therefore explores other, more personal barriers to integrating palliative care and oncology, and offers some solutions for each. I thank Dr. Michael Levy for this opportunity. Dr. Levy and I were oncology fellows together in the late 1970s, but in the 1980s, as I pursued the mysteries of myelopoiesis, he began his pioneering work to relieve the pain and suffering of his patients with cancer. In 1999, he became the President of the American Academy of Hospice and Palliative Medicine, and in 2001 was
awarded both its Distinguished Service and Lifetime Achievement awards.

**Barrier 1**

**Problem: “Learned Helplessness”**

Oncologists practicing in the era before the advent of effective palliative medications or communication training may have acquired a “learned helplessness.” Most oncologists, including department chairs and fellowship directors, are likely to have been trained before palliative care became a subspecialty and before evidence-based guidelines on the management of symptoms and psychological disorders and sophisticated communication techniques were readily available. Oncologists who have not worked closely with palliative care teams are unlikely to be aware of what palliative care expertise can offer their patients, or what “best supportive care” entails. A recent review of Institutional Review Board (IRB)–approved trials of chemotherapy with best supportive care versus best supportive care alone found no standardization of the best supportive care arm in 12 of the 14 trials. As von Roenn and Temel argue, “These failures underscore the inadequate knowledge base among academic oncologists, who have trained the oncologists in practice, serve on IRBs, and perform most of the peer-review for publication.”

Until my sabbatical with the Pain Service at Memorial Sloan-Kettering Cancer Center in 1992, I was one of those academic oncologists. But for their help, I would have continued practicing oncology without what I now regard as core skills in pain and symptom assessment and management, and would not have gained the tools to explore and alleviate the many other sources of suffering for my patients. I would not have known about palliative care social workers, chaplains, or nurse practitioners. I was certainly never taught communication skills. I recall vividly the first patient to whom I broke the news that she had acute leukemia. My lack of skill led her to respond, “I’m all right dear; are you?” And if a patient asked me, “Why did I get lung cancer?” I completely missed the spiritual concern and answered, “Because you smoked.”

Symptom management training was similarly lacking. Like most oncologists practicing in the last 3 decades of the twentieth century, I learned pain management through trial and error. As the treatments became more toxic, even the patients equated the nausea and vomiting the drugs caused with their effectiveness. Those who gave cisplatin before 5-HT3RI and NK-1 inhibitors were available, using metoclopramide at 100 mg/m² every 2 hours for 6 cycles (along with lorazepam and diphenhydramine to control the metoclopramide’s side effects), know what I’m talking about.

Trying to manage cancer pain with only short-acting morphine, Percocet, and meperidine was just as bad. Until the first consensus recommendations on pain management were published in 1994, no standard existed for comprehensive assessment and management of cancer pain, a problem that affects 30% of patients with cancer at diagnosis and 75% by the end of their lives. Until the mid-1980s, when Silastic indwelling catheters were proven safe for use in neutropenic, infected patients, intravenous lines were replaced every 48 hours.

I began to assume that suffering was the price my patients had to pay. Patients certainly didn’t discuss it with me in those days, nor did my teachers or colleagues or the nurses in our infusion suites. I assume that was because we couldn’t ameliorate the side effects of what were, in the case of cis-platinum, curative therapies. I am concerned that this “learned helplessness” still exists among oncologists trained in this era and in their trainees, many of whom now lead oncology departments or fellowship programs, and that it remains a barrier to consulting palliative care, and to including rotations with palliative care teams in the fellowship curriculum.

It may even remain a barrier to recognizing when enough is enough. Medical oncologists share something with their surgical colleagues: like surgeons, oncologists often induce suffering to prolong life. And like surgeons, they form a fiduciary bond with patients, promising them that they will get them through the hard times. Especially when the dying is partly caused by a complication of the chemotherapy, this bond may prevent the needed shift to a focus on comfort care and delay a palliative care consult.

Whatever the reasons, the current system is not working. Oncologists still cite “trial and error” as the way they learn pain management. With only oncologists, who are not palliative care experts, to teach them, a remarkable lack of progress in pain management and end-of-life care skills has occurred among oncology fellows and practicing oncologists.
Solution: Mandate Education and Expect Competence

To help stop this learned helplessness from being perpetuated, fellow education in core palliative care competencies by palliative care experts or expertly trained oncology fellowship directors and key faculty should be mandated, and practicing oncologists should be expected to demonstrate basic palliative care competence. The evidence base is now there; the past 15 years have seen major scientific advances in palliative care for patients with cancer. The research has improved not only management of symptoms and complications of cancer therapies but also communication between patients and practitioners and relief of psychological and spiritual distress of patients with cancer at all stages of disease. Based on this evidence or (in the absence of definitive studies) expert consensus, several useful palliative care guidelines were produced: the National Framework and Preferred Practices for Palliative and Hospice Care Quality; the 2005 American Pain Society guidelines for the management of cancer pain; Multinational Association of Supportive Care in Cancer guidelines for antiemetic therapy; NCCN Guidelines for Supportive Care, including pain, antiemetic therapy, distress, and palliative care; and ASCO guidelines for antiemetic therapy. ASCO supported the creation of core palliative care educational resources for trainees (the Palliative Care Review and Symptom Management Curriculum, both available through the ASCO University Bookstore) along with Education in Palliative and End-of-Life Care (EPEC) - Oncology for practicing clinicians.

Increasing literature is available on successful training in communication for faculty who will be teaching fellows, and for the fellows themselves, and practitioners, and expert communication is considered a core competency for oncology fellows (although oncologists, not palliative care experts, assess the fellows). Although they do not relish talking about advance directives, if they have to, most patients want to discuss them with their oncologists, and practical evidence-based advice exists for discussing prognosis, breaking bad news, and conducting other difficult conversations. ASCO has also developed materials for patients to use both in the area of symptom management (www.cancer.net) and advance care planning. Palliative care questions are included in the oncology Medical Knowledge Self-Assessment Program and the American Board of Internal Medicine certifying examination.

What Should Be Taught?: Core palliative care skills should include pain and symptom assessment and management, and assessment and treatment of psychological sources of distress, such as anxiety, depression, and delirium. Fellows should learn to look for the presence of social, spiritual, and existential distress, and learn to collaborate with experts in these areas. Communication skills, such as breaking bad news, responding to the affective component of conversations with patients and their families, and caring for dying patients, are also core palliative care skills, as are self-care and prevention of compassion fatigue (see later discussion). Finally, fellows should know when to consult a psychiatrist or palliative care expert. As Von Roenn and Temel recommend, “When the complex nature of symptoms and/or psychosocial issues exceeds the experience of the medical oncologist, referral to a tertiary level of palliative care may be needed.”

Who Should Teach Palliative Care Skills?: Fellows should be taught and observed by board-certified palliative care experts whenever possible. Although it is not a requirement for the designation, all NCI-designated comprehensive cancer centers have palliative care teams, as do 78% of non-NCI-designated facilities caring for patients with cancer, including most of those housing oncology fellowship programs.

Lectures are insufficient. Medical oncology fellows often rotate through clinics with experts in each area of oncology in their first clinical year. Similar rotations in palliative care clinics or inpatient services that care for oncology patients would enable fellows to acquire the palliative care competencies they need, and to experience the depth and range of the expertise available to them from their palliative care consultants. These assignments would elevate the acquisition of palliative care expertise to the same level as acquiring other basic oncology knowledge and could be evaluated just as rigorously.

If fellowship directors plan to be responsible for training their fellows in palliative care competencies, they and their key faculty need personal supervision by board-certified palliative care experts in train-the-trainer sessions that include observed communication exercises (eg, role playing).
Practicing Oncologists Can Also Acquire Primary Level Palliative Care Skills: Practicing oncologists can acquire palliative care basics through continuing medical education courses (eg, Supportive Oncology [www.supportiveoncology.net], or Practical Aspects of Palliative Care [HMS Center for Palliative Care Education; www.hms.harvard.edu/pallcare]), handbooks,13 or the ASCO materials mentioned earlier. At Dana-Farber Cancer Institute, to maintain clinical privileges, all prescribing clinicians must pass an online examination (with online reference materials) in cancer pain management. Quality Oncology Practice Initiative measures can also be used to assess palliative care practice and provide feedback to staff.

A palliative care clinician can be added to the tumor board or can give a workshop for the practice. After a half-day workshop I conducted, which included a discussion of pain, delirium, nausea and vomiting, and malignant bowel obstruction, and addressed patient requests for hastened death, compassion fatigue, and role playing, the practice developed algorithms for recognizing which of their patients would benefit from a palliative care consult and scheduled monthly discussions with me to review their toughest clinical cases.

Palliative care consultants can also teach communication skills that would make oncologists more comfortable, even in difficult conversations. For example, when the oncologist tells a patient that she has recurrent disease, or that he is not well enough to receive more chemotherapy, the anger or despair in the response of the patient or family can feel like an attack. Oncologists skilled in communication, however, will know that the emotions are not directed at them. They will also know how to help the patient or family member feel “heard,” how to name the emotion in the room and, by so doing, “defuse” it, and will feel comfortable allowing the distressed person to say all they need to, before making a plan that fits the new reality they will be facing.17

As the practice I worked with learned more palliative care communication skills and understood more about their own barriers to discussing advance care planning, they began to have the conversations with people still receiving active treatment but who likely had only months to live. And they reported these discussions to me and their colleagues with a well-earned sense of accomplishment. Recently, they sent one of their physician assistants for palliative care training to be an ongoing resource to the practice.

Situations in Which a Palliative Care Specialist Would Be Particularly Useful: A physician who is a cancer survivor wrote, “As a physician, I have observed the hesitancy to consult with palliative care, often as a result of misperceptions or not recognizing when it would be beneficial. My suggestion would be to refer several patients and see what a difference the team can make.”38 In addition to referring patients with refractory symptoms or difficult family dynamics, 2 situations in which a consult is likely needed are:

1. Patients who seem not to understand that they have advanced disease. Palliative care practitioners can be particularly helpful for patients who cannot seem to understand that their time may be short.39 “Palliative care specialists can help guide patients and their families, and patients’ oncologists, through the transition from disease-modifying therapy to care focused on palliative goals.”40 Patients randomized to meet with a palliative care practitioner within the first 3 weeks of diagnosis of advanced lung cancer were more able than those who received standard oncology care to understand their prognosis accurately, to know that their cancer was incurable and plan accordingly, and to receive less parenteral chemotherapy near the end of life.41

2. Patients who do not want their oncologist to play a palliative care role in their care. Oncologists might suppose that since their team has an excellent rapport with their patients, they do not need a palliative care team involved. But some oncologists who are also board-certified in palliative care have found that their patients do not want to be as open with them about their hopes and fears, or even the extent of their distress, as were the patients they saw in their palliative care roles when they were fellows. One former fellow told me that her patients told her they needed her to be a “fighter” for them, not a supporter. So she began collaborating with a palliative care colleague to whom she referred these patients.

Barrier 2

Problem: Compassion Fatigue

Quite appropriately, oncologists focus on the fight against cancer. But they all know, going into the specialty, that despite their best efforts, most patients with metastatic solid tumors will die of their cancer.
I received no training in how to handle that emotionally or in the compassion fatigue I was at risk of developing.

**What is Compassion Fatigue?:** Compassion fatigue is the detachment and depersonalization that develops in therapists who care for people who have experienced extreme suffering (eg, torture, rape) and in clinicians, such as emergency department specialists, oncologists, and palliative care physicians, who are emotionally affected by the trauma their patients experience. It develops in clinicians whose patients have prolonged downhill courses and who suffer severely, and in patients about whom clinicians feel “guilty, insecure, frustrated, or inadequate.”

Compassion fatigue can lead to stress-related medical disorders, anxiety, depression, substance abuse, and family disruption. Some of its manifestations resemble those seen in patients with post-traumatic stress disorder, including hyperarousal, reexperiencing, and avoidance. In oncologists, hyperarousal may manifest as anger at staff, colleagues, or even patients with refractory disease or their families. Reexperiencing may take the form of dreams or nightmares about conversations with patients whose disease is relentlessly progressive. Avoidance can manifest as detachment, depersonalizing patients, withdrawing from patients who are doing badly, rounding when patients are likely to be asleep and the family not there because it is too painful for the oncologist, and even absenteeism.

I believe that unrecognized compassion fatigue among oncologists inhibits timely discussions about prognosis and the true burdens and benefits of therapy, and that even making referrals to palliative care may open doors that oncologists experiencing compassion fatigue are not yet emotionally prepared to go through. The reluctance to consult is likely not even to be conscious, but it is real and arises partly from painful memories of the many tough meetings oncologists have had with dying patients and their families. If they do not consult palliative care, they and their patients may not be asked to face the fact that time may be shorter than they had all hoped for and that plans must be made to accommodate that sad reality. Therefore, when I hear, “He’s not ready for palliative care,” I sometimes wonder, “Who isn’t ready?”

Cumulative grief and compassion fatigue lead to burnout, those who cannot bear to sit and talk with patients, because they see their patients’ impending deaths and feel helpless in the face of that prospect, cannot offer the presence these patients need. Without an opportunity to express those griefs and diminish their power, clinicians have less and less “room” for emotional engagement with their own families, colleagues, and patients.

**Solution: Acquire Skills to Prevent Burnout**

The first step is for fellows and practicing oncologists to acquire the core skills of conducting difficult conversations through mentoring from palliative care and oncology experts using the techniques referenced earlier. Second, identify dysfunctional beliefs, such as: “Limitation of knowledge is a personal failing; [medical doctors] should bear responsibility alone; altruistic devotion to work and denial of self is desirable; it is professional to keep one’s uncertainties and emotions to oneself.” Third, forgive oneself, accept limitations, and accept praise; recognize and let go of mistakes and opportunities lost or mishandled; and search for sources of pain and get help to learn to live with it, or do what needs to be done to help diminish it. Balint groups for oncology fellows facilitated by skilled psychologists, palliative care social workers, or trained oncologists can serve as a forum for discussion and exploration of grief-inducing clinical encounters, and for normalizing these feelings. Training should also include how it feels to say goodbye to a dying patient, and why it is important to do so both for patients and clinicians, and the value of writing bereavement letters and making mentored bereavement calls. Clinicians can also obtain self-awareness or mindfulness training, both of which have been shown to help prevent burnout.

In some cases, collaborating with palliative care teams will make the process bearable. These groups can help clinicians conduct those tough conversations and later process the grief, leaving them better able to support and be empathetic with their patients, more aware that the limitations of medicines not theirs, and proud of what they can offer them.

**A Genuine Partnership:** Acquiring primary-level palliative care skills and freely consulting palliative care for the more challenging situations clinicians encounter during the everyday practice of oncology will empower them: they will be able to alleviate their patient’s suffering earlier and more often, feel skilled in communicating in even emotion-laden conversations, and use effective strategies for de-
briefing after those terrible conversations they have all too often. The palliative care team should be consulted early and often for patients who develop refractory symptoms, families who present communication challenges, and anyone for whom the support would be welcome. In so doing, oncologists will make palliative care an integral part of comprehensive cancer care.

References

5. Oncology 2011;25(13).