

Incorporating Palliative Care Into Oncology Practice: Why and How

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Abstract: The provision of specialty palliative care alongside oncology care is now recommended by the American Society of Clinical Oncology (ASCO) on the basis of multiple randomized trials showing that it leads to better symptom control, less depression and anxiety, improved quality of life, improved caregiver quality of life, and even longer survival. That said, simply not enough palliative care specialists are available to provide concurrent care, so oncologists are tasked with providing the greatest part of primary palliative care. It is useful to think of primary palliative care as comprising 2 skill sets, or “bundles”: the first symptom assessment and management, and the second communication. Symptom assessment begins with the use of a standardized scale that emphasizes the assessment of anxiety, depression, physical symptoms, and coping strategies. Communication requires knowing how much information the patient and family want, especially about prognosis, and involves shared decision making. It also encompasses advance care planning, starting with the identification of a medical power of attorney and proceeding to a discussion about hospice and end-of-life treatment choices. The communication skill set includes providing caregiver support and spiritual care referral, making culturally appropriate decisions, and providing a specific statement of non-abandonment near the end of life. If specialty palliative care is involved, data show that the effect on quality of life and end-of-life choices is most meaningful if consultation is started at least 3 months before death. In this article, we provide a brief overview of the benefits of incorporating palliative care into routine oncologic practice and offer clinical pearls on how best to deliver the tenets of palliative care in the outpatient and inpatient settings.

Why Oncologists Need to Provide Palliative Care

In 2018, the American Society of Clinical Oncology (ASCO) issued a practice guideline stating that every patient with advanced cancer

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Table 1. Use of a Modified Edmonton Symptom Assessment Scale During a Routine Oncologic Visit

Symptom/Concern	How to Ask About It
	Begin with the question, “Are you bothered by <i>x</i> symptom?” If the answer is yes, ask, “On a scale of 0 to 10, where 0 means the symptom is absent and 10 means the symptom is of the worst possible severity, how would you rate your difficulty?”
Pain	If present, ask, “Which areas of the body hurt the most?”
Tiredness (lack of energy)	If present, ask, “What activities make you tired?”
Drowsiness (feeling sleepy)	If present, ask, “At what times of the day do you feel most drowsy? How are you sleeping?”
Nausea	If present, ask, “What makes you most nauseated?”
Lack of appetite	If present, ask, “Are there certain foods that you prefer to eat?”
Shortness of breath	If present, ask, “What activities make you most short of breath?”
Depression (feeling sad)	If present, ask, “What makes you most depressed?”
Anxiety (feeling nervous)	If present, ask, “What makes you most anxious?”
Lack of well-being	“How would you describe your overall well-being?”
Spiritual concerns	“Are you bothered by any spiritual or religious issues?”
Financial distress	“Are you having difficulty paying for your medicines or care?”

should be seen by a palliative care specialist team within 8 weeks after diagnosis.¹ This robust conclusion was based on multiple clinical trials conducted in the outpatient clinic showing better symptom control; improved quality of life for both patient and caregiver; less distress, anxiety, and depression despite greater awareness of the prognosis; and even better survival. In 2 recent trials of patient-reported outcomes (PROs) of symptom management, absolute survival benefits of 6² and 12³ patients for every 100 treated were observed at 5 and 2 years of follow-up, respectively. These results have been borne out in the real-world setting; patients with lung cancer who received palliative care cost Medicare thousands of dollars less per person, with a hazard ratio for death of 0.83.⁴ The addition of outpatient and inpatient palliative care also changed end-of-life care patterns away from the intensive care unit (ICU) and hospital toward home and inpatient hospice, allowing a better utilization of ICU resources and saving payers thousands of dollars per person.⁵

On the inpatient side, multiple studies have shown better symptom control, less patient and caregiver distress, better use of the ICU, slightly shorter length of stay, and thousands of dollars in health savings per patient.^{5,6} The sicker the patient and the earlier the involvement of palliative care, the greater were the savings.⁷ (Although the palliative care specialty is not intended to save money, the business case is easy to make.)

What the ASCO guideline did not mention was that not enough palliative care professionals are available to provide all this specialty service. Although some hospices extended their services to begin providing palliative care (meaning that oncologists still had to say “hospice”),

others did not. In addition, the quality of care and services varies substantially from hospice to hospice, with no professional or consumer-driven ratings available to recommend one over another. So, how can oncology practices fill the gap between the recommendations for concurrent palliative care and the reality that we must do most of it ourselves?

How Oncologists Can Provide Palliative Care

In the simplest terms, palliative care consists of 2 critical components, which some have termed “bundles”⁸: symptom management and communication. We are all trained in symptom management, and we usually start with the question, “How are you?” This question on its own is inadequate, however. For example, oncology patients are known to downplay symptoms to be “good patients” or to avoid a change in therapy. One study found that open-ended questioning led patients to volunteer a median of just 1 symptom, whereas a structured survey uncovered a median of 10 symptoms, 53% of which were distressing.⁹ Palliative care specialists are trained to use a formal symptom assessment tool, such as the Edmonton Symptom Assessment Scale (ESAS).¹⁰ As shown in Table 1, this tool requires that patients be asked about specific common symptoms, and that the symptoms be quantified and charted longitudinally. The most recent ESAS iterations even ask clinicians to inquire about spiritual distress and financial distress, which we have included in Table 1. The questioning does not need to be long or involved; just ask, “Are you bothered by *x* symptom? From 0 to 10, how bad is it?” All our patients are used to grading pain from 0 to

Table 2. Recommended Questions for Outpatient Palliative Care

Recommendation	Questions to Ask/Words to Use
Ask how the patient likes to receive medical information.	“Are you the sort of person who likes to know all the details?” “Would you like to discuss the possible prognosis, or what might happen?” Comments: -There is no one-size-fits-all approach
Ask patients to explain their understanding of their medical situation.	“What is your understanding of your situation?” -This is the only way to know if patients have a realistic view of their future, including their thoughts on “curability” and survival. -Getting this out in the open lets you and them speak more freely about what might happen.
Defer to the patient’s wishes when a scan comes back with evidence of progressive disease or other bad news.	“Would you like to discuss what this means?” -You know the prognosis has worsened and options have become more limited. They likely do not want this discussion. -This approach gives patient an opt-out opportunity. -In one study, patients were told about a bad scan result in only 4 of 64 cases. ³⁷
Conduct a hospice information visit when you think a patient has 6 months or less to live.	“When patients have serious cancer, such as yours, I like to have them meet with hospice so they know what kinds of services are provided.” -This brings up “hospice,” which invariably leads to the question, “How much time have I got?” so we can forecast for them. -The transition to hospice is far easier if it is a planned transition, not abandonment. -Tell patients, “No matter what, we will be with you every step of the way.” A colleague calls this a “specific statement of non-abandonment” and finds that it makes the transition easier for all concerned. -Nearly everyone wants to have some idea of their probable life span. ³⁸
Always ask the patient, “How are you coping?” After the patient answers, ask the caregiver, “How are <i>you</i> coping?”	These questions were one of the main distinguishing aspects of this landmark trial. ³⁹ The palliative care team asked these questions routinely. There were no notations of their use in any of the usual oncology care charts. It is possible to reframe even bad news within potentially achievable good goals, but the process starts with an understanding of current coping. ⁴⁰

10, so this part of the assessment is not difficult to accomplish. Although we may not like to ask questions about financial distress, evidence is accumulating that a strong association exists between financial distress and anxiety, depression, and poor quality of life,¹¹ so we should be aware of it.

Some palliative medicine tools are available that may not have made it into the oncologist’s tool kit. For instance, the ASCO guideline on anorexia and cachexia does not recommend any medications or interventions beyond a nutritionist consult.¹² A recent trial of 5 mg of olanzapine taken at night, however, showed a dramatic decrease in nausea unrelated to chemotherapy (nausea score of 9/10 reduced to 2/10 at 24 hours and to 1/10 at 1 week) and similar beneficial effects on appetite.¹³ We often use olanzapine in our practice because of its beneficial effects in patients with insomnia¹⁴ and neuropathic pain,^{15,16} and anecdotal evidence and now recent trial data suggest that it helps to restore appetite. Gabapentin is not the first drug to choose to treat chemotherapy-induced neuropathy¹⁷; duloxetine is the only drug with proven efficacy.¹⁸ However, gabapentin works

well for chronic centralized cough,^{19,20} and hiccups.²¹ Topical menthol (we use Mineral Ice, which contains 2% menthol, because it is inexpensive and readily available at any drugstore) appears to help relieve the symptoms of chemotherapy-induced neuropathy, especially tingling, numbness, and hypersensitivity.²²

The skill set for communication is harder to implement than that for symptom management. Many of us are not trained in communication, but it can be learned.²³ Communication is personally draining; the necessary continual delivery of bad news is disturbing and a vivid reminder of our own mortality—what the nurse and palliative care pioneer Nessa Coyle has called “the existential slap.”²⁴ So many times, the tough conversations do not happen in oncology practice, and people’s lives end in the ICU or hospital, or they spend a brief time in hospice. Among 118 patients with solid tumors who died as inpatients at our institution, a discussion regarding the goals of care was documented for only 24%, even though 84% had seen their oncologist in the month before admission.²⁵ Also at our own institution, 47% of patients dying of gastrointestinal cancer used hospice for less than

Table 3. Dos and Don'ts of Inpatient Palliative Care

Do	Reasoning
Consult the palliative care team as soon as a patient with advanced cancer is admitted.	Most providers recognize when a patient is sick enough that they would not be surprised if the patient were to die within the next year. People admitted to oncology wards for symptom management have an average life span of just 3 to 4 months, so palliative care is appropriate. ⁴¹
Involve the palliative care team and social worker during family conferences.	In addition to a discussion of symptom management and goals of care, involving the palliative care team allows the patient to get answers to some of the more nuanced questions regarding home hospice and inpatient hospice, which are often not fully understood by providers not trained in the same area.
When the hospital lacks a dedicated palliative care team, consult social work or the case manager team.	Social workers and case managers are essential sources of assistance on the technical details of appropriate hospice placement and its interaction with insurance benefits, patient finances, and incurred caregiver stress.
Don't	Reasoning
Don't call the palliative care team after the patient has been in the hospital for days.	The sooner you call, the earlier a palliative care team can work on establishing rapport, assessing symptoms, clarifying goals of care, and assessing if hospice or concurrent care is appropriate.
Don't call the palliative care team just before discharge.	Rapport with the patient and family is key to a good relationship.
Don't send the patient to subacute rehabilitation (SAR) if you would not be surprised if they were to die in the next 6 months, or "to get stronger for immunotherapy." Consider hospice instead.	SAR does not work in these instances, and most of these patients would be better served with hospice. ⁴² Of 358 patients sent from the oncology floor to SAR, 49% returned to the oncology clinic. A total of 21% died within 30 days, and because they were at SAR, only 31% used hospice. Only 33% ever received any anticancer treatment. Call a palliative care consult at the same time you ask social work for SAR placement.

7 days,²⁶ which would not pass muster with the National Quality Forum or ASCO.

We have listed some practical tips for incorporating palliative care communication in the outpatient (Table 2) and inpatient (Table 3) setting. Many of us do not have experts in outpatient palliative medicine available, but most sizable hospitals have a team, so the recommendations may differ.

The most important part is to get started with the difficult conversation. We have made a temporary tattoo that goes on the volar forearm so that we can remind ourselves to ask the most difficult questions (Figure).²⁷ One of the authors of this paper (QH) keeps a note pinned on his phone that contains the questions on the tattoo. Just as we have a semi-scripted talk about beginning adjuvant chemotherapy or beginning immunotherapy in breast cancer, we should have a simple set of words to start these conversations. Just being honest and saying things such as, "I am worried about you, and where we are going with this cancer" can start the conversation.

The data are reasonably clear that getting palliative care involved early, whether we do it ourselves or include a specialist team, makes a difference in end-of-life care. In one study, when patients were seen by a palliative

care team at least 3 months before they died, end-of-life hospitalizations were reduced and society saved at least \$6000 per person. By contrast, involvement during the last month of life made no difference in these measures.²⁸ That is not to say that we should not bother with palliative care near the end of life. Within the last 30 days of life, palliative care involvement was far more likely to lead to hospice referral, and hospice referral reduced the chance of readmission by a factor of 4.09.²⁹

In a large propensity score-weighted trial of inpatient palliative care for persons with cancer, the involvement of palliative care on day 2 of hospitalization (to define the goals of care, as well as to alleviate symptoms) reduced the total hospital cost by 24%.³⁰ The total hospital cost was reduced by 34% when patients with the highest number of comorbidities received palliative care. It is worth reiterating that earlier involvement of palliative care results in greater savings.³¹ These cost savings came from reduced expenditures per day and reduced total length of stay, as palliative care principles allowed patients to be discharged to an appropriate level of care more quickly.³² As stated earlier, palliative care was never intended to save money—no specialty is—but any oncologist effort is welcomed that reduces admissions and readmissions, saves ICU beds for

those who can most benefit, and improves care and quality of life. We call it “better care at a cost we can afford.”

Discussion

We have outlined some symptom management and communication skills used by palliative care specialists that can be readily adopted by oncologists. We miss many opportunities to address advance care planning, or we may wait to address it until patients have only a month left to live.³³ According to national guidelines, it is prudent to begin planning a full year before death can reasonably be expected.³⁴

Although the benefits of specialty palliative care are now well recognized and noted in this article, one need not look back any further than the last 20 years to realize how recent these developments are. Dame Cicely Saunders founded the first known hospice, called St. Christopher’s Hospice, in London in 1967. Medicare’s hospice benefit was made permanent by Congress in 1986, and the first palliative care program in a US academic hospital was established only a year later. The subspecialty of Hospice and Palliative Medicine is itself quite new, having been established by the American Board of Medical Specialties in 2006. In 2000, the penetration of palliative care programs at US hospitals with 50 beds or more was less than 25%. As of 2016, penetration was approximately 75%, with 1831 of 2436 hospitals (with more than 50 beds) reporting the presence of a specialty palliative care team.

These developments were not happenstance; rather, they were the result of a concerted effort to gather data from a consistently aging population that was living longer with more comorbidities and being cared for in a health care system with multiple layers of complexity, in which increasingly more diagnostic procedures and treatments were at the disposal of clinicians. Such gathering of data together with changes at the institutional and policy level have made palliative care a center point for those who have advanced disease with a significant symptom burden, and who require appropriate counseling on transitioning from a philosophy focused on treatment to one focused on quality of life. Notably, in the United States, 2017 was the first year since the early 20th century in which the home surpassed the hospital as the place where people most frequently died. Between 1997, when the first Institute of Medicine report on dying, titled “Approaching Death,” was published, and 2015, when the second report, titled “Dying in America,” was published, the field of palliative care became an integral part of the modern American hospital.^{35,36}

Yet significant care gaps remain, especially in the number of palliative care physicians and advance practice providers trained in the discipline. This shortage is



Figure. The temporary tattoo we use to prompt difficult discussions.

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compounded by the fact that practicing oncologists may receive inadequate prior training during medical school and residency, and even during fellowship, when the major focus remains on learning the diagnostic schema for a wide variety of malignant and nonmalignant diseases, along with the ever-expanding list of possible treatment options. A focus on the underlying pathology and treatment of disease often accompanies oncologists into practice. Although it may be difficult for oncologists to adopt the entire palliative care specialty into their practices, a recognition of the most salient points may help reduce avoidable distress for patients during the time when they are most vulnerable. We hope this article will encourage oncologists to adopt best practices into the daily care of their patients.

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