

# Joining Together to Improve Outcomes: Integrating Specialty Palliative Care Into the Care of Patients With Cancer

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## Abstract

This article addresses the misconception that patients with cancer should undergo a definitive “transition” to palliative care at some point in their trajectory, and instead proposes that a gradual shift should occur from primary palliative care provided by the oncologist to specialty palliative care when the need exists. The goal is to help practitioners identify which patients are in need of specialty palliative care, suggest when oncologists should consider making a referral, and offer a model for sharing the responsibilities of care once palliative care clinicians become involved. This model enhances the patient and family experience through improving symptom control and quality of life, and may even prolong survival. It also minimizes patients’ perception of abandonment at the end of life, while reducing the risk of physician burnout in practicing oncologists. Lastly, the misconceptions of oncologists are addressed regarding how patients and families will accept the idea of a palliative care consultation, and suggestions are offered for responding to patient and/or family resistance to referral when it arises. (*JNCCN* 2013;11[Suppl 4]:S38–S46)

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### Learning Objectives

Upon completion of this activity, participants will be able to:

- Identify patients in need of specialty palliative care and develop a model for integrating specialty palliative care into the care of patients with cancer
- List strategies for effectively communicating with patients and caregivers, including responding to resistance to referral for specialty palliative care

### Case Presentation

Mr. R is a 67-year-old widower who was diagnosed 1.5 years ago with KRAS-mutant colon cancer metastatic to his liver and lungs. His oncologist discussed the incurable nature of his disease; the treatment plan, including 2 to 3 lines of standard chemotherapy options; and average survival of approximately 2 years. Over the next 12 months, Mr. R had stable disease on FOLFOX combination chemotherapy, and tolerated treatment well, although he gradually became increasingly withdrawn and passive during visits. His oncologist attempted to screen for depression, but Mr. R denied this symptom. In addition, on several occasions Mr. R resisted discussion of advanced directives and code status, saying it was not the right time to talk about these issues.

#### Ending #1

At 18 months after diagnosis, Mr. R's disease progresses. He requires several admissions for complications of his disease, including obstructive jaundice with cholangitis, falls at home, acute kidney injury from dehydration, and failure to thrive. The oncologist meets with Mr. R and his daughter to discuss further treatment options. Given the progression of Mr. R's disease, his poor performance status (ECOG performance status [PS] 3), and persistent hyperbilirubinemia, the oncologist recommends against further chemotherapy and urges enrolling with hospice. Mr. R's daughter, who is an only child and a registered nurse at a local hospital, interjects tearfully that despite her father's need for a wheelchair

at the visit, he is very active at home, and that he is "a fighter" who "will do fine" with more chemotherapy. Palliative care is consulted to meet with the patient and his daughter. In 2 visits the daughter remains highly resistant to accepting her father's imminent death; the clinicians note extreme anticipatory grief at losing her remaining parent. Mr. R is too overshadowed by his daughter's distress during those visits to open up about his reasons for being withdrawn. A few weeks later, Mr. R dies in the emergency department, having been brought there in a panic by his daughter.

#### Ending #2

The palliative care team is consulted 6 months after Mr. R's diagnosis because of his withdrawn demeanor and inability to discuss his advance directives and goals of care. Mr. R confides that he sometimes thinks that chemotherapy is only prolonging his dying process, but he worries about leaving his only daughter behind. He is not depressed but seems to lack direction for the last part of his life. Over the next 12 months, he engages in multiple discussions about legacy building and life completion work with the palliative care team. Ultimately, he states his goal is to live long enough to prepare his daughter for his death and afterwards. During a joint meeting with his daughter, Mr. R and the palliative care team allow her to share her anticipatory grief at losing her remaining parent. She and her father openly mourn the loss of more time together. Mr. R's daughter and the patient state that when he begins to die, they would not want to prolong that process, so an out-of-hospital do not resuscitate form is completed.

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receives emotional support from the hospice social worker throughout the dying process. Bereavement services from the hospice will assess for complicated bereavement up to 13 months after Mr. R's death.

## Introduction

This article addresses the misconception that patients with cancer should undergo a definitive “transition” to palliative care at some point in their trajectory. In fact, the best possible care of these patients should incorporate principles of palliative care from the beginning, and oncologists and specialty palliative care providers should collaborate to provide palliation throughout the spectrum of a person's illness experience (Figure 1). The NCCN Clinical Practice Guidelines in Oncology for Palliative Care define palliative care as:

A special kind of patient- and family-centered health care that focuses on effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to patient/family needs, values, beliefs, and cultures. The goal of palliative care is to anticipate, prevent, and reduce suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care begins at diagnosis and should be delivered concurrently with disease-directed, life-prolonging therapies and should facilitate patient autonomy, access to information, and choice. Palliative care becomes the main focus of care when disease-directed, life-prolonging therapies are no longer effective, appropriate, or desired. Palliative care should be initiated by the primary oncology team and then augmented by collaboration with an interdisciplinary team of palliative care experts.<sup>1</sup>

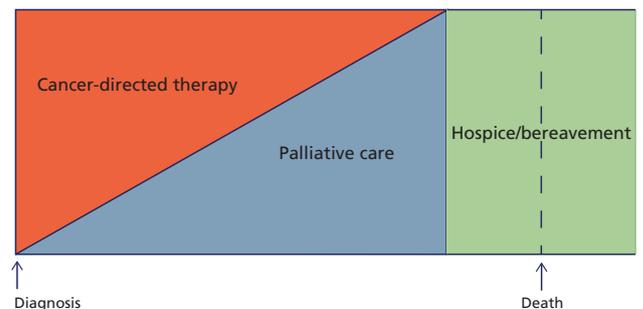
Thus, the transition is not an abrupt switch from oncology to specialty palliative care, but rather a gradual shift from primary palliative care provided by the oncologist to specialty palliative care when the need exists. This article helps practitioners identify which patients are in need of specialty palliative care, suggests when oncologists should consider making a referral, and offers a model for sharing the responsibilities of care once palliative care clinicians become involved. This model should not only enhance the patient and family experience through improvements in symptom control and quality of life

and prolonged survival<sup>2</sup> but also minimize patient perceptions of abandonment and reduce the risk of physician burnout in practicing oncologists. Lastly, the misconceptions of oncologists are addressed regarding how patients and families will accept the idea of a palliative care consultation, and suggestions are offered for responding to patient and/or family resistance to referral when it arises.

## When to Integrate Specialty Palliative Care Into Patient Care

The ideal time to consult palliative care is not when the patient chooses “the palliative route” or has no further chemotherapy options, but rather when specialty level palliative care is required to provide optimal care for the person and family experiencing a serious illness.

These patients can be identified systematically or on a case-by-case basis. In some cancer centers, for example, referral to palliative care is standard for patients with newly diagnosed incurable cancers, such as non-resectable pancreatic cancer or stage IV lung cancer. Alternatively, on an individual case-by-case basis, oncologists should consider referring patients to palliative care for either refractory symptoms or unusual difficulty with coping and decision-making. Many patient and family units can absorb distressing news, cope with the associated emotions and grief, and then make rational decisions about their current and future goals of care. The patients and families who struggle with these tasks are the ones who benefit from the addition of specialty palliative care. Extensive literature attempts to identify abnormal incorporation of medical information, coping, and decision-making, but the authors posit that most oncologists “know it when they see it.” A common concern voiced at the time of palliative care referral is that the patients “just don't get it.” Other triggers for refer-



**Figure 1.** Palliative care integrated into the continuum of care.

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ral to specialty level palliative care may be found in a recent publication by Drs. Abernethy and Quill (Table 1),<sup>3</sup> and in the Criteria for Consultation With Palliative Care Specialists in the NCCN Guidelines (Table 2).<sup>1</sup> Ideally, early recognition of patients appropriate for referral to palliative care services allows the specialists adequate time to build rapport, explore the psychosocial context within which the patient's disease is occurring, develop strategies for incorporation of information, and bolster coping strategies. Rarely are 1 or 2 visits sufficient for this process, and therefore involvement at least 3 to 6 months before cessation of chemotherapy would be ideal to affect outcomes.

Applying these criteria to the present case, Mr. R's primary oncology team noted challenges with his emotional state and ability to engage in decision-making around code status despite having stable disease while on chemotherapy. In Ending #2, using Abernethy and Quill's criteria,<sup>3</sup> the team consulted palliative care services earlier to help with "management of more complex depression, anxiety, grief, and existential distress." In addition, NCCN Guidelines advocate for a consult based on Mr. R's "inability to engage in advanced care planning and care plan." Ending #1 illustrates that waiting for the "traditional" delayed transition to specialty palliative care near the end of life may be too late to detect and impact the troubled trajectory of care for a patient.

### The Need for Shared Care in Complex Patients

It is clear from the present case that the biomedical model of disease ignores the emotional, social, spiritual, and financial impact of serious illness on a

patient and his family. Many oncologists were drawn to their field by a desire to guide patients compassionately through the emotion and pain of a cancer journey, but one clinician can only do so much, and the need is great. Earle<sup>4</sup> best encapsulates this sentiment in his article "It Takes a Village":

Contrary to our self-image, the evidence suggests that, in many (or even most) situations, we are not always able to provide patients with cancer with all of their primary care, psychosocial support, symptom palliation, or possibly even end-of-life discussions. This is not to suggest that we see our role as merely giving chemotherapy but...our patients might be better off if we do not try to do everything ourselves. It takes a village to help our patients through this journey. The quality of end-of-life care can be better when we take a team-based approach.

In addition, oncologists may vary, personally and professionally, in how comfortable they feel providing the extensive and necessary support recommended by NCCN in patients with advanced cancer with "years," "years to months," and "months to weeks" left to live. Table 3 lists topics that, in the authors' experience, may be best addressed with a team-based approach, including specialty palliative care.

### Models for Sharing Care of Complex Patients

Bruera and Hui<sup>5</sup> describe different conceptual models of palliative care provision for patients with complex cancer (Figure 2). In the Solo Practice Model, oncologists and their staff provide both cancer-directed assessment/treatment and pallia-

**Table 1** Expectations of Primary Palliative Care Versus Specialty Palliative Care

Primary Palliative Care	Specialty Palliative Care
Basic management of pain and symptoms	Management of refractory pain and other symptoms
Basic management of depression and anxiety	Management of more complex depression, anxiety, grief, and existential distress
Basic discussions about: <ul style="list-style-type: none"> <li>• Prognosis</li> <li>• Goals of treatment</li> <li>• Suffering</li> <li>• Code status</li> </ul>	Assistance with conflict resolution regarding goals or methods of treatment: <ul style="list-style-type: none"> <li>• Within families</li> <li>• Between staff and families</li> <li>• Among treatment teams</li> </ul>
	Assistance in addressing cases of near futility

Adapted from Quill TE, Abernethy AP. Generalist plus specialist palliative care—creating a more sustainable model. *N Engl J Med* 2013;368:1174; with permission.

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**Table 2 Selected NCCN Criteria for Referral to Specialty Palliative Care**

Criteria for Referral to Specialty Palliative Care	Examples
Uncontrolled or difficult-to-control symptoms	Neuropathic pain Incident or breakthrough pain Rapid escalation of opioid doses History of drug or alcohol abuse Multiple "allergies" or a history of multiple adverse reactions to pain and symptom management interventions Multiple coincident symptoms
Moderate-to-severe distress related to cancer diagnosis and/or therapy	High distress score (>4) Requests for hastened death Spiritual or existential crisis
Serious comorbid physical, psychiatric, and psychosocial conditions	Family/caregiver limitations Inadequate social support Intensely dependent relationships Financial limitations Limited access to care Family discord Unresolved or multiple prior personal/familial losses
Life expectancy <6 months	Metastatic solid tumors/stage IV tumors Poor performance status (ECOG≥3 or KPS≤50) Hypercalcemia Brain or CSF metastasis Delirium SVC syndrome Spinal cord compression Cachexia Malignant effusions
Patient/family concerns about course of disease Patient/family difficulties with decision-making	Patient concerns regarding care of dependents Cognitive impairment Communication barriers Inability to engage in advance care planning
Patient/family requests for palliative care Risk of significant health care use at end of life	Frequent ED visits or hospital readmissions ICU admissions with multiple complications or requiring lengthy ventilator support
Health care team issues	Compassion fatigue Moral distress Lack of agreement among professional team about benefit/utility of interventions

Abbreviations: CSP, cerebrospinal fluid; ED, emergency department; ICU, intensive care unit; KPS, Karnofsky performance status; SVC, superior vena cava. Adapted from Levy MH, Back A, Baker JN, et al. NCCN Clinical Practice Guidelines in Oncology: Palliative Care. Available at: NCCN.org. Accessed May 8, 2013.

tive care. In the Congress Practice Model, multiple services are consulted to address each symptomatic or psychosocial need individually. The Integrated Care Model, which the authors recommend, integrates specialty palliative care early in the oncolog-

ic care of selected patients. This model has numerous benefits. First, compared with the Solo Practice Model, sharing the clinical care for these complex patients and their families can reduce the risk of burnout among oncologists, allowing practitioners

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to continue dedicating themselves fully to their jobs and the health of the population they serve, for a more sustainable system.<sup>6,7</sup> Second, the Integrated Care Model allows the oncology and palliative care teams to customize the responsibilities each will assume for a given patient/family unit. The proportion of oncology-to-palliative care visits will vary among patients and also over time as fewer antineoplastic options are available. Third, compared with the Congress Practice Model, the Integrated Care Model offers patient-centered care: the patient and family are spared the burden and potential confusion of multiple different consultants who may not communicate with each other and whose recommendations may not be informed by the patient's values and goals. Finally, this collaboration, if begun soon after diagnosis and continued to the end-of-life, avoids a "hand off" of the patient from oncology to specialty palliative care. This prevents the patient and family from feeling abandoned and may thus impact bereavement outcomes.<sup>8</sup> It also reduces resistance to the referral: with the Integrated Care Model in place, an oncologist can honestly state to patients and families that a palliative care consultation is an added layer of support "which we offer to many of our patients," and does not represent giving up or that death is imminent.

Regarding the 2 case presentations, readers may have noticed a difference in the "closure" achieved in Ending #2 for the oncologist, Mr. R, and his daughter. The oncologist feels at peace having given the medically appropriate recommendation to forego further antineoplastic therapy, the daughter has had time to complete "unfinished business" with her father and acquired a legacy that will give her comfort once he has died, and Mr. R leaves this world with the comforting thought that his daughter will be alright. As recommended in the NCCN Guidelines for Palliative Care, clinicians who care for patients with can-

cer should strive to optimize health outcomes for not only the patient but also the family and/or caregivers who will survive their loved one (to view the most recent version of these guidelines, visit [NCCN.org](http://NCCN.org)).<sup>1,9</sup>

### Barriers to Integration of Specialized Palliative Care

Research has shown that the average American health care consumer has little to no idea what palliative care is; this finding corresponds to that of the authors' clinical experiences. Furthermore, when consumers were educated about palliative care, they were extremely positive about it and felt it should be available to patients with serious illness.<sup>10</sup> Yet at MD Anderson, after the Palliative Care program was renamed Supportive Care, a significant increase occurred in the total number of referrals and in the proportion of patients with early-stage cancer referred, and shorter times from hospital registration and diagnosis of advanced cancer to supportive care consultation were seen.<sup>11</sup>

So what gets in the way of earlier referral for appropriate patients? One explanation for the MD Anderson experience could be the negative perceptions of palliative care on the part of the oncologists rather than the patients. A survey of medical oncologists and other health care professionals from the United States revealed that 60% of participants considered palliative care to be synonymous with hospice and end-of-life care, and 23% reported the term *palliative care* was a barrier to referral.<sup>12</sup> The authors believe the solution is not to simply change the name, but rather change cultural perceptions. If oncologists only refer their patients to palliative care (whatever it is called) at the end-of-life, then these practitioners will continue to view the concept of palliative care in that limited way, and perpetuate that view to

**Table 3 NCCN Recommended Topics for End-of-Life Preparation**

Provide anticipatory guidance on dying process
Encourage the patient to review and revise personal priorities, identify "unfinished business," heal interpersonal relationships, and put affairs in order
Provide anticipatory grief support and end-of-life education
Explore fears about dying and address anxiety
Explore family concerns about the patient's plan and seek resolution of conflict between patient and family goals and wishes

Data from Levy MH, Back A, Baker JN, et al. NCCN Clinical Practice Guidelines in Oncology: Palliative Care. Available at: [NCCN.org](http://NCCN.org). Accessed May 8, 2013.

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patients, families, and their medical colleagues. If oncologists instead refer to palliative care earlier, they will see the added benefits throughout the course of disease, changing their own perceptions and those of the culture at large.

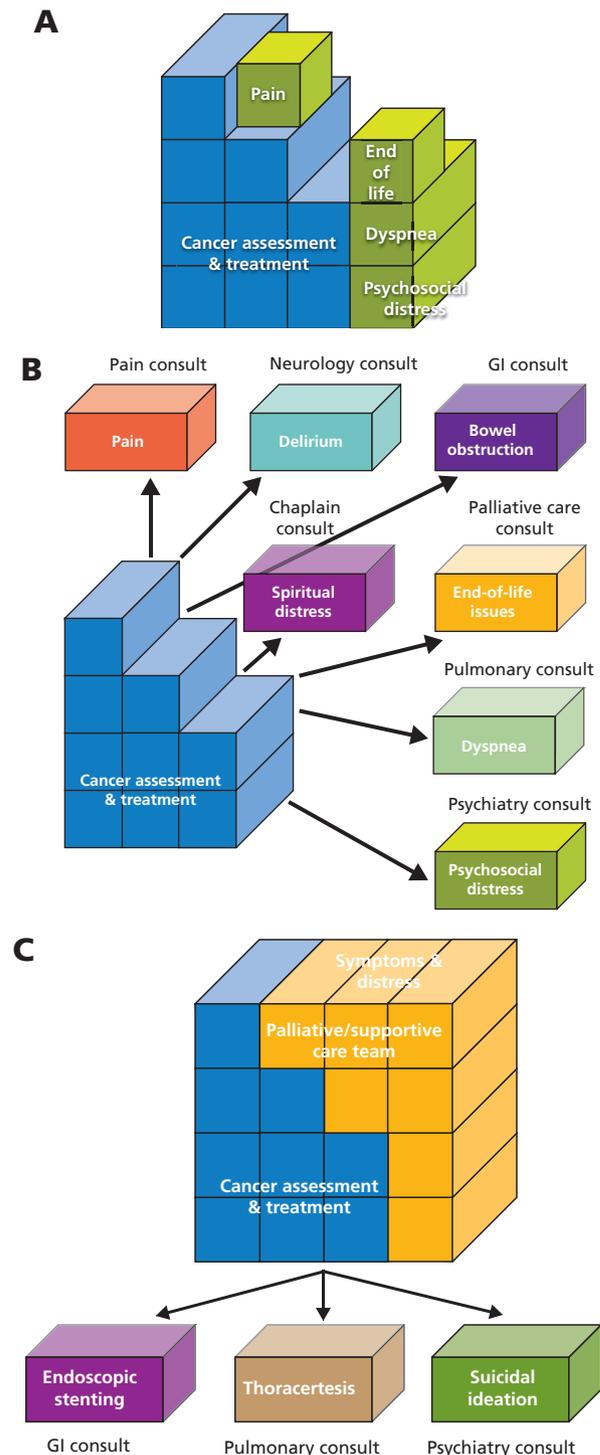
Oncologists may also delay or avoid palliative care referral because they believe they already provide this care, which for some of these practitioners represents a lack of training in the principles and practice of palliative care—a “learned helplessness” about managing complex symptoms or inadequate coping by their patients. Because they have not had the opportunity to train or work with palliative care practitioners, they “don’t know what they don’t know.” Another barrier can be the underrecognized cumulative grief oncologists may experience from caring for patients who suffer and die despite their best efforts; this grief can lead to a nihilistic view that suffering must be a normal part of the dying process.<sup>13</sup> When the principles of palliative care are integrated into the training of oncology fellows, and palliative care practitioners are integrated into the clinical care of patients with cancer, these misperceptions and gaps in knowledge begin to correct themselves.

Returning to the present case and reflecting on Ending #2, the authors posit that Mr. R’s daughter is likely to recommend the involvement of palliative care to other members of her community when they are faced with life-limiting illness, and that Mr. R’s oncologist might do the same. This simple act repeated multiple times by multiple different family members and clinicians caring for patients within the Integrated Care Model eventually effects a culture shift in the population as a whole about what palliative care and oncology care can provide.

### Strategies to Overcome Patients’ Resistance to Palliative Care Referral

When the barrier to referral is perceived to be within the patient or family unit, the authors have found the following strategies to be useful: focusing on the patient’s greatest need, clarifying misconceptions about palliative care, and being explicit about palliative care being part of the cancer team.

First, the oncologist can tailor the description of palliative care by emphasizing their focus in the area of the patient’s greatest concern. For example,



**Figure 2** Conceptual models for integrating palliative care into the management of patients with cancer. (A) The Solo Practice Model: the oncology team manages all aspects of care. (B) The Congress Practice Model: the oncology team delegates different aspects of care to various subspecialists. (C) The Integrated Care Model: the oncology team is responsible for cancer therapy/management, whereas the palliative care specialist is responsible for most symptom and psychosocial issues. Further referrals are made by either oncology or palliative care. From Bruera E, Hui D. Conceptual models for integrating palliative care at cancer centers. *J Palliat Med* 2012;15:1261–1269, with permission. Abbreviation: GI, gastrointestinal.

“they are the symptom experts” (or “they help with the emotional aspects of facing a tough disease” or “they help with planning for the future”). Often, an initial referral to palliative care for a symptom issue, even if that symptom could be easily managed by the oncologist, provides a “foot in the door” with skittish patients, allowing providers to establish rapport. Once trust is built between the patient and the palliative care specialist, more sensitive emotional topics can be broached.

Second, the authors suggest that the oncologist ask whether the patient and family have ever heard of palliative care before to expose any preexisting misconceptions. Regardless of the answer, oncologists should explicitly distinguish palliative care from hospice, and explain that palliative care is appropriate for patients throughout the cancer trajectory, from diagnosis onward, and not just at the end of life. Further emphasis should be placed on the role of palliative care in optimizing patients’ quality of life and providing emotional support to families/caregivers.

Lastly, communicating clearly with the patient that the palliative care team is part of the larger multidisciplinary cancer team is critical. In light of this, oncologists might consider inviting the palliative care consultant to meet the patient by sitting in on an oncology visit; after the oncologist is finished, the palliative care practitioner can complete their assessment alone. Another strategy is to invite palliative care providers to see patients while in infusion. In the authors’ experience, patients who are reluctant to meet with palliative care are more receptive when the consultant comes to them rather than the other way around. Perhaps most importantly, the palliative care team must actually be incorporated within the oncology team, whether by attending tumor board, meeting with the oncologist and infusion nurse during regular patient panel reviews, or through sharing clinic space. Finally, although the literature is sparse on this topic, integration often results in a palliative care specialist who is well versed in oncology care, including the wide variation of prognoses, treatment options, and adverse treatment effects for different malignancies. This may alleviate oncologists’ concerns about losing control of information flow if they know the palliative care specialist has adequate cancer-related knowledge and patient experience. This leads to a camaraderie and collegiality that is essential in the co-management of patients with complex cancer.

Another strategy worth mentioning is one that destigmatizes palliative care consults by considering them standard for any patient with noncurable advanced cancer, such as that used by Temel et al.<sup>2</sup> Given that in 2009 only 60% of NCI-designated and 22% of non-NCI-designated cancer centers had outpatient palliative care available,<sup>14</sup> there is clearly a resource use issue where the demand would surely outstrip the ability to provide high-quality, valuable services. With this in mind, a cancer center or practice might choose to select 1 or 2 disease groups they deem most in need, and for all others use an algorithm with suggested palliative care consult triggers that can be used by any member of the health care team.

## Conclusions

As cancer care and cancer-directed therapies become increasingly targeted and specific, the symptom, social, spiritual, and emotional needs of the patients themselves remain critical and must not fade into the background. To ensure this, NCCN and other leading organizations exhort oncologists to provide primary palliative care to their patients throughout the course of illness. For a subset of patients, however, primary palliative care is not sufficient, therefore it is critical for these oncology teams to recognize that need and refer these patients to specialty palliative care. This shift toward a team-based approach enhances the care and experience of the patient and family and also reduces burnout for oncologists, increasing the sustainability of their practices. Through asking the palliative care team to collaborate in the care of patients with cancer, the treatment plan can be better individualized and the appropriate amount of palliative care can be titrated where it is needed the most. The authors believe that for high-risk patients, oncologists and cancer centers should incorporate specialty palliative care as early in the disease course as possible. They have highlighted a model for oncology-palliative care collaboration, and offered suggestions to overcome resistance to referral. Lastly, the medical community needs to let go of the outdated view that palliative care is the “end-of-life team,” and recognize specialty palliative care for what it is: added support for high-risk patients and families.

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