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Integrating Palliative Care in Oncology:

The Oncologist as a Primary Palliative Care Provider

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Abstract

The provision of comprehensive cancer care in an increasingly complex landscape necessitates that oncology providers familiarize themselves with the application of palliative care. Palliative care is a learnable skill. Recent endeavors in this arena have demonstrated that providing palliative care is part and parcel with providing compassionate and high-quality cancer care, specifically as it pertains to physical and emotional outcomes for patients and their caregivers alike. The basic tenets of providing palliative care emphasize: frequent and honest communication, routine and systematic symptom assessment, integration of spiritual assessments, and early integration of specialized hospice and palliative care resources as a patient's circumstances evolve. This article will endeavor to review and synthesize recent developments in the palliative care literature, specifically as they pertain to the oncologist as a primary palliative care provider.

Keywords

Palliative care; end of life care; hospice care; advance care planning; prognostication

Oncologists are increasingly faced with the challenge of providing comprehensive care to patients in an evolving landscape. Of all patients diagnosed with metastatic cancer, current treatment will permit nearly half to continue living for a period of years after their initial diagnosis.¹ We must use our growing arsenal to provide personalized,² compassionate, and cost-effective care that translates into better outcomes and quality of life (QOL) for our patients.

Palliative care, which is a distinct medical specialty that is often included within the continuum of comprehensive cancer care, is "specialized medical care for people with serious illnesses, focused on providing patients with relief from the symptoms, pain, and stress of a serious illness"—whatever the diagnosis and regardless of the prognosis.³ "The goal is to improve quality of life for both patient and family."³ This must necessarily be distinguished from *end of life* or *hospice care*. Medicare defines the latter as "care of patients with a physician-estimated life expectancy of 6 months or less."⁴

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Palliative care is part of best practice in oncology, as endorsed by the American Society of Clinical Oncology (ASCO), European Society for Medical Oncology, the National Comprehensive Cancer Network (NCCN), and the Society for Surgical Oncology.^{1,5} Many oncologists agree that integrating palliative care at the time of an advanced cancer diagnosis enhances patient care and complements their practice.⁶ However, although most oncologists believe that they already practice palliative care, recent studies suggest that our performance in this regard is in need of significant improvement.^{7,8}

What Kinds of Palliative Care Exist?

Palliative care is a resource provided by a team of doctors, nurses, and other specialists who are (or work along with) the patient's longitudinal care providers to provide an added layer of support. As such, palliative care can be meaningfully used at any stage of a serious illness —including circumstances where it is provided concomitantly with curative therapy. Primary palliative care⁹ is provided on a regular basis by the longitudinal oncologist and care team. Secondary palliative care is provided by teams of individuals with dedicated expertise in this discipline. This resource can be provided either in outpatient programs or in an inpatient unit. Tertiary palliative care is provided by specialized teams of providers with advanced expertise in the management of symptoms and pain, including but not limited to implantable drug delivery systems, palliative sedation, and management of advanced delirium. This article will emphasize the rationale behind and methods/resources for providing quality primary palliative care for the medical oncologist.

What Is the Best Model?

We do not know what the core or essential elements of palliative care when provided alongside primary oncology care are, but there are good models. Capital Caring and Hospice has partnered with US Oncology to provide palliative care doctors and advance practice nurses in the private practice oncology office. This model was based on what services were reimbursable. Patient symptoms were reduced by 21%, with high provider satisfaction and remarkable time savings of almost 4 weeks for the practice by shifting symptom management to the palliative care provider.¹⁰ Similar models of "modified" palliative care have been successfully integrated into usual oncology practice at numerous other centers, including academic centers in the United States and Canada.¹¹

Why Does Providing Palliative Care Matter?

In recent years, there has been a growing body of academic scholarship investigating the impact of early and/or integrated palliative care. Several of the recently published studies have offered more modern, consistent, comprehensive, and carefully controlled investigations of palliative care interventions. Improvements in QOL,^{12,13} symptoms,^{12–14} mood,^{12–14} patient satisfaction,^{15,16} caregiver burden,¹⁷ and completion of advance directives^{13,14,16} have been demonstrated. Decreased utilization of clinical and financial resources,^{13,15,16} decreased treatment toxicity,¹⁸ and improved survival have also been observed.¹³ We have listed some of the consistent findings in Table 1.

Palliative care provided concomitantly with standard oncologic care in patients with advanced cancer results in noninferior—and often superior—outcomes with regard to QOL, symptom relief, mood, patient satisfaction, advance care planning, and survival. This is despite the decreased intensity and use of medical and financial resources at the end of life in patients receiving palliative care. Moreover, no studies have demonstrated harm associated with early or integrated palliative care. These findings have been validated in several recently published systematic reviews of the palliative care literature.^{19–21}

How Do I Provide Primary Palliative Care in the Oncology Office?

We have listed some of the most important parts of primary palliative care in Table 2.

Communicate Honestly and Effectively: Ask, Tell, Ask... and Listen

Honest and effective communication with cancer patients and their families regarding diagnosis, prognosis, and likely treatment outcomes and toxicities remains a central tenet in the oncology care continuum. Yet, even so, studies have shown that patients with advanced cancers commonly share an inaccurate perception of treatment effect, goals, and outcomes—often overestimating survival. In a recently published study by Weeks et al.,²² nearly 80% of patients with metastatic lung and colo-rectal cancer reported that chemotherapy was "very/ somewhat/a little likely to be curative." Patients with advanced-stage disease operating with a belief in a high likelihood of survival greater than 6 months were 2.6 times more likely to favor life-extending therapy over comfort measures—but without any improvement in survival.²² Physicians caring for such patients can be similarly challenged in their efforts to accurately prognosticate—and have been shown to overestimate prognosis by a factor of 5.²³ Thus, providers, patients, and families with inaccurate perceptions of treatment outcomes may opt for therapies that incur significant risk with only modest potential for benefit.

Several prognostic scales have been developed for and validated in cancer patients to aid providers in having frank discussions about prognosis and treatment outcomes.^{24–26} Such efforts are important to patients and families and can contribute to better outcomes. Temel and colleagues²⁷ have previously demonstrated that a better understanding of the incurable nature of their disease is associated with improved survival in lung cancer patients. This is possibly due to less use of ineffective and toxic fourth- and fifth-line chemotherapy. We have listed some helpful prognostic tools in Table 3.

Such discussions should necessarily occur on a repeating basis.²⁸ Poignant triggers for such conversations include when the disease progresses, when medical complications of the cancer occur, and when the performance status declines. We let the natural history of the disease prompt us to have these conversations (as shown in Figure 1). Emphasis should be placed on negotiating the content and pace of the discussion to best meet the patient and family's needs, that is, ask, tell, then ask again. "How much would you like to know?" "What kind of information would be most useful to you?" We should always be sure to confirm comprehension. "Can you tell me what you are taking away from this discussion?"

Although such skills do not necessarily evolve with time and/or experience,²⁹ they can be learned.^{30–37} In recent years, specific workshops and longitudinal programs such as Oncotalk have been developed and effectively implemented. After participation, providers were much more likely to use skills useful in discussing end-of-life issues and breaking bad news.³⁰

These conversations are critically important, but we do not have them or document them often or well enough. In the most recent nationwide survey of lung cancer patients, only half had any mention of hospice 2 months before death—by any physician.³⁸ Only 22% had a doctor tell them about impending death, and when it did occur (in many cases only a month before death), it was often not the primary oncologist who had the conversation.³⁹ The data are clear that many oncologists prefer not to have these conversations until "there are no more treatment options left"⁴⁰—when often, it is too late to plan.

We recommend the use of the decision aid and prompts from the ASCO lung cancer guideline,⁴¹ which gives the oncologist a script to use for advance care planning.

Assess Symptoms Consistently, Then Intervene

That patients with advanced cancer experience multiple concurrent symptoms has been well demonstrated in the literature.⁴² Several symptom assessment tools are currently in existence. What matters is not so much *which* tool is used, but that *a tool* is used consistently and the results documented. Their value is not simply in the 1-time assessment, but also in the evolution over time. Symptom assessment is more than just an evaluation of pain and performance status. Delirium, nausea (with or without vomiting), constipation, anorexia, insomnia/fatigue, anxiety, depression, and dyspnea are among the other considerations that significantly impact patients' QOL. Such assessments not only facilitate meaningful therapeutic interventions, but may also assist in improving the accuracy of providers' survival predictions. In multivariate analyses, confusion, anorexia, fatigue, cachexia, weight loss, dyspnea, and dysphagia all served as independent predictors of survival.⁴³

We use a simple rounding tool available from the Center to Advance Palliative Care (Table 4) to assess for the most common symptoms.

Help Patients and Families Prepare With Purpose: Advance Directives and Addressing Spiritual and Family Needs

As of 1991, the Patient Self-determination Act passed by the US Congress mandated that health care institutions provide information about advance directives to adult patients upon admission to their facility. Advance directives are legal documents that communicate a patient's preferences about his/her medical care (what to do/what not to do, and who will perform decision making) in the event that the patient becomes incapacitated and is unable to make such decisions for himself/herself. Important components include the living will and medical power of attorney. In a living will, a patient specifically outlines his/her decisions about future medical care, including (but not limited to) do-not-resuscitate or do-not-intubate orders, use of life-sustaining equipment (dialysis machines, ventilators), placement of enteral feeding tubes, and organ donation. The medical power of attorney is the

component of the advance directive that specifies another individual who is empowered to make decisions about the patient's medical care if the patient is otherwise unable to do so. Since passage of the Patient Self-determination Act, completion of advance care plans has increased from 21% of patients hospitalized with serious illness to nearly 40%.^{44,45}

Completing an advance directive is an integral component of oncology care, because at least half of our patients will die, and nearly all those with metastatic cancer will die. Studies indicate that patients view completion of the advance directive as a way of preparing for future uncertainty and incapacity by minimizing the burden of death on loved ones.⁴⁶ However, in a 2003 report from the Agency for Healthcare Research and Quality, less than 50% of severely/terminally ill patients had an advance directive in their medical record.⁴⁷ Recent studies have indicated that access to early and/or integrated palliative care significantly increases the frequency with which advance directives are completed by patients with advanced illness, with reported completion rates as high as 91% in those groups where a formal palliative care intervention was involved.^{13,14,16}

Help Patients and Families With Their Spiritual Needs

Recent data show that 86% of our patients want us to be aware of their spirituality and think it is an important part of cancer care.⁴⁸ There is accumulating evidence that programs that do spiritual assessments and have active chaplaincy programs have better satisfaction⁴⁹ and fewer in-hospital deaths.⁵⁰ In fact, if spiritual care is provided by the medical team, in distinction to community services, patients with terminal illness are more likely to use hospice and have better QOL scores.⁵¹ We use the FICA⁵² (F—faith, I—importance, C— community, A—address) Spiritual History Tool (www.gwumc.edu/gwish/clinical/fica.cfm) or simply ask: "Is religion or spirituality important to you?" (and have established links to chaplains when the person says "Yes… I have neglected that part of my life…."). Key elements of palliative care include knowing that patients want us to address these issues and to have predetermined resources to address these issues.

Facilitate Hospice Referrals Early

In current practice, hospice care is often initiated too late for patients and their families to derive maximal benefit. Nearly 30% of cancer patients in the United States enter hospice with less than 1 week to live.⁵³ On average, most patients spend less than 20 days in hospice care,⁵³ and less than 55% of Medicare cancer patients ever use hospice.⁵⁴ Many oncologists view the optimal timing for hospice referral as that when "there are no treatment options left." However, as the evidence for early and integrated palliative care continues to rise (reviewed previously here), our professional societies (ASCO, NCCN, European Society for Medical Oncology, and others) are increasingly encouraging primary cancer providers to reconsider the optimal timing and utilization of resources such as hospice at the end of life.^{1,5} Several investigators have now demonstrated increased use of hospice resources when referrals are made early,⁵⁵ and there is a 10-fold increase in referrals when palliative care is consulted.⁵⁶

Initiating a hospice referral when a patient still has 3 to 6 months to live can provide patient, family, and providers alike the opportunity to maximally understand, accept, and utilize this

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resource at the end of life. Indeed, although accurate forecasting in cancer patients is often considered more art than science, certain clinical features are reliable in identifying patients with less than 6 months to live.²⁴ The development of malignant hypercalcemia (excluding patients with newly diagnosed breast cancer and multiple myeloma), malignant ascites, malignant pleural/pericardial effusion, and malignant bowel obstruction are among these tell-tale scenarios.⁵⁷

How Can I Access Resources to Help Me?

Primary palliative care should be part of most oncology practices now, but the practice patterns observed in studies such as the Temel lung cancer study suggest it is not being done.^{7,13} The NCCN has readily available guidelines that detail the components of palliative care. ASCO University has excellent tools on palliative care (http://university.asco.org/palliative-care-review), as does the Center to Advance Palliative Care Web site (http://www.capc.org/). We use the natural history of the illness as prompts to remember to deliver the best palliative care at the most meaningful intervals. An up-to-date list of providers is available at www.getpalliativecare.org.

What Are the Barriers to Accessing and Integrating Palliative Care?

First, we need more clinic- and community-based nonhospice palliative care programs. The pioneering programs of Capital Caring and US Oncology suggest that such programs are productive and self-sustaining. Second, we need more dedicated secondary/tertiary palliative care providers to meet the growing demand, as there is a workforce shortage in both oncology and palliative care. Finally, we need better financial support/reimbursement infrastructure to support early palliative care interventions—most resources in this regard are available only in the hospice/end-of-life setting. The available data show that provision of "expanded access" programs, such as the Aetna Compassionate Care program of allowing hospice to be involved with concurrent chemotherapy, showed that hospice days were increased, hospital days at the end of life were reduced 7-fold, and intensive care days reduced nearly 10-fold.⁵⁸ Based on the equal survival and better end-of-life care with earlier hospice involvement and a 22% savings in the last 40 days of life, Aetna has made this routinely available.⁵⁹

CONCLUSIONS

With recent advances in diagnostic, therapeutic, and supportive care strategies for our cancer patients, we as oncologists and longitudinal care providers must empower ourselves to offer comprehensive, compassionate, and high-quality care to a growing population of medically complex patients. Early and effective integration of palliative care into our daily best practice means that we recognize, understand, and are agile with the opportunities to meaningfully intervene and resources that will help us to do so. The provision of primary palliative care is learnable and dependent on patient-centered communication occurring at regular/disease-prompted intervals, routine and systematic use and documentation of symptom assessments, completion of spiritual assessments, and early involvement of specialized hospice and palliative care providers.

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FIGURE 1.

Using the natural history of advanced cancer to guide palliative care involvement.

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TABLE 1

Outcomes From Randomized Trials of Palliative Care Performed in the Last 10 Years

				Out	comes		
First Author, Year	Symptoms	Quality of Life	Mood	Satisfaction	Resource Use	Advance Care Planning	Survival
Bakitas et al. (2009), ¹² nurse-led intervention	Improved, $P = 0.06$	Improved, $P = 0.02$	Improved, $P = 0.02$	Not measured	No difference	No difference	No difference
Brumley et al. (2007), ¹⁵ team intervention	Not measured	Not measured	Not measured	Improved, $P < 0.05$	Cost \$7500 less, $P = 0.03$, hospital days reduced by 4.36 (P < 0.001) ED visits reduced by $0.35 (P = 0.02)$	Not measured	No difference
Gade et al. (2008), ¹⁶ team intervention	No difference	No difference	No difference	IPCS greater satisfaction with care ($P = 0.04$) and communication ($P =$ 0.0004)	Costs \$6766 less <i>P</i> < 0.001). Net cost savings of \$4855 (<i>P</i> < 0.001); longer median hospice stays (24 vs 12 d, <i>P</i> = 0.04)	IPCS patients had more ADs at discharge than UC patients (91.1% vs 77.8%; $P < 0.001$)	No difference
Temel et al. (2010) ¹³	Improved, $P = 0.04$	Improved, $P = 0.03$	Less depression, $P = 0.01$	Not measured	Less aggressive care, $P = 0.05$, \$2200 per person savings	More ADs documented in PC group, $P = 0.05$	11.6 vs 8.9 mo, P = 0.02
ED indicates emergency depa	artment; IPCS, interd	lisciplinary palliative	care service; UC, usu	al care; AD, advance dir	ective; PC, palliative care.		

TABLE 2

Components of Office-Based Primary Oncology Palliative Care

- Ask, tell, ask. Always ask people how much they want to know and what they do know. Then tell them, in understandable words. Then ask: "What is your understanding of your situation?" 1
- At each transition point (when changing treatments or prognosis), ask: "What are you hoping for?" and "What is your understanding 2 of your situation?
- Always do a symptom assessment. 3
- 4 At least some of the time, do a spiritual assessment.
- 5 Make a "hospice information referral" when the patient still has 3-6 mo left to live.
- 6 Audit hospice referrals, like quality oncology practice initiative (QOPI) does.
- Set up "best practices" for seriously ill patients who have less than a year to live. 7
- Take advantage of decision aids to help those patients who want to know their prognosis really know their prognosis. 8
- Use some "palliative care pearls" in your practice, such as olanzapine for nausea, ginger for nausea, ginseng, or dexamethasone for 9 fatigue and better QOL.

TABLE 3

Prognostic Tools Available to Oncologists

Tool	Usefulness	Actions That Oncologists Can Take
Performance status (PS)	Decline in PS predicts worse response to chemotherapy and shortened survival	"Ask, tell, ask" about the level of information requested; advance care planning; hospice information visits
Clinical characteristics	 Reliable predictors of survival <6 mo Hypercalcemia Malignant pleural effusions Malignant ascites Multiple brain metastases 	With a few exceptions such as gastrointestinal stromal tumor (GIST) and human epidermal receptor (HER)-2 positive/amplified breast cancer, these always indicate mean survival of <6 mo and can lead to the actions above while pursuing treatment.
Palliative Performance Scale	Reliably predicts survival in days, weeks, or months with bedside observations	Available with interpretation at End of Life/Palliative Education Resource Center (EPERC) http:// www.eperc.mcw.edu/EPERC/FastFactsIndex/ff_125.htm
Palliative prognostic score	Reliably predicts survival into 3 categories based on clinical observations, white count, and lymphocyte count	Available with interpretation at EPERC http:// www.eperc.mcw.edu/EPERC/FastFactsIndex/ff_124.htm

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TABLE 4

The Memorial Symptom Assessment Scale Condensed Rounding Tool*

Reported by: Patient	Careg	jver 🗆 R	N 🗆 MD. Ask	:: "Are you	Bothered by.				
Unable to Respond:	es 🗆 No								
Delirium: 🛛 Yes 🗆 No									
Pain (or 0–10) Tire	dness	Nausea	Depression	Anxiety	Drowsiness	Anorexia	Constipation	Dyspnea	Secretions
0									
1									
2									
3									
4									
7									
* Scoring: 0 = none, 1 = a lith	tle bit, 2	= somewh	nat, 3 = quite a	lot, 4 = vei	y much, 7 = re	fused.			