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Integrating Supportive and Palliative Care in the Trajectory of Cancer: Establishing Goals and Models of Care

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INTRODUCTION

Tom, a 50-year-old man with metastatic pancreatic cancer, was referred by his phase I physician to our supportive care center for symptom management. He was initially diagnosed with pancreatic cancer involving the liver approximately 6 months before this visit. He developed progressive disease despite three lines of systemic therapy, including four cycles of gemcitabine and cisplatin, three cycles of gemcitabine and vorinostat under phase I, and two cycles of fluorouracil, leucovorin, and oxaliplatin 6. His clinical course was complicated by recurrent venous thromboembolic events.

Tom arrived at the supportive care clinic in a wheelchair and accompanied by his wife. He complained of right upper quadrant pain, particularly with inspiration, despite taking morphine continuous release 30 mg twice a day. He had also experienced severe fatigue, weakness, constipation, decreased appetite, and weight loss of 25 kg during the previous 5 months. Eastern Cooperative Oncology Group performance status was 4. Edmonton Symptom Assessment Scale (0 = no symptom, 10 = worst possible) revealed pain 8, fatigue 4, nausea 0, depression 0, anxiety 0, drowsiness 0, appetite 10, well-being 5, dyspnea 5, and sleep 5.

On examination, he looked thin, was tachycardic and tachypneic, and had significant tenderness over the right upper quadrant. He was also experiencing severe weakness and had to use both hands to lift his legs to move around in bed. He lived with his wife and one son at home, but he had difficulty coping with the worsening symptoms.

We adjusted his pain medications and laxatives, gave him a dose of methylnaltrexone in the clinic, recommended a home-safety evaluation, and provided supportive/expressive counseling. He expressed the desire not to receive any more cancer treatments, and we discussed the transition to hospice care so he could get more support at home.

At the end of the visit, Tom said, "Oh, I wish I had seen you sooner. Why wasn't I referred here

earlier?" Tom went home with hospice care and died 10 days later.

ROLE OF PALLIATIVE CARE IN PATIENTS WITH ADVANCED CANCER

Tom's story is all too familiar. Patients with advanced cancer frequently develop devastating physical and psychosocial symptoms (Table 1).² These symptoms require individualized assessment and management. In addition, patients frequently develop functional decline, along with spiritual and financial concerns. Their primary caregivers and other family members may also experience physical and emotional distress,³ necessitating a combination of counseling and education about the patients' illnesses. Furthermore, patients and their families require discussions regarding goals of care and advanced-care planning for their future health care needs.

Palliative care is "... an approach that improves the quality of life of patients and their families, facing the problem associated with lifethreatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."4 During the last few decades, palliative care has acquired expertise in symptom management, psychosocial care, communication, complex decision making, and transition of care. Since the opening of the first palliative care unit in Montreal, Canada, in 1976,⁵ these programs have become available at a large number of acute care hospitals and cancer centers around the world.⁶ Palliative medicine is now a recognized specialty in many countries, and it has a growing evidence base for improving quality of care.^{7,8} However, patients continue to be referred to these programs in low numbers and late in the trajectory of illness.9 The purpose of this article is to review the barriers to early palliative care access, to discuss a theoretical model for integrated care, and to propose a practical approach to the care of patients with advanced cancer. Both authors are medical oncologists with research interests in supportive/palliative oncology.

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Symptom	Frequency (%)
Anorexia	30-92
Pain	35-96
Fatigue	32-90
Dyspnea	10-70
Delirium	6-93
Depression	3-77

TIMING OF PALLIATIVE CARE REFERRAL

In addition to the more traditional inpatient consultation service and palliative care units,^{10,11} palliative care teams increasingly provide outpatient services, so primary teams can refer patients early in the trajectory of illness.¹² There has been a significant increase in the use of palliative care by oncologists.¹³ However, the referral of patients to palliative care occurs late in the trajectory of illness at an average of 30 to 60 days before death.^{9,14} The majority of families referred to palliative care programs state that they would have preferred an earlier consultation.^{15,16} Indeed, early referral to palliative care can facilitate timely diagnosis and treatment of symptoms, longitudinal psychosocial support, and counseling, as well as a gradual transition of care. There is emerging evidence that early incorporation of palliative

care principles can improve patients' quality of life while minimizing caregiver distress and aggressive measures at the end of life.^{17,18}

Given that almost all patients with cancer seen by the palliative care team are referred by oncologists rather than self-referred, oncologists have a critical role in deciding on the need for and the timing of referral. Although not every patient would require a supportive/palliative care consultation, all should have access to good symptom control and emotional support when the needs arise, and those with refractory physical and/or psychosocial distress should be referred promptly.

One of the key barriers to early referral is the misunderstanding that palliative care is only provided at the end of life once patients have exhausted all cancer treatment options. Some oncologists have expressed the concern that a referral to palliative care would destroy a patient's hope.¹⁹ It is important to recognize that patients do not need to choose between cancer treatments and supportive/palliative care. Rather, they can take advantage of the expertise of both the oncology and the palliative care teams in optimizing quantity and quality of life under a simultaneous care model.^{20,21} This is particularly important in the new era of targeted therapy, which has seen an explosion of novel therapeutic options that are less toxic than traditional chemotherapy, making it feasible for patients to receive cancer treatments closer to the end of life.

In this regard, the use of the term "supportive care" instead of "palliative care" might be conducive to earlier referrals, given that this term is perceived as less distressing by oncologists.²² We have since renamed our consultation service and outpatient clinic but not our palliative care unit, adopting the term "supportive care" to facilitate



Fig 1. The use of a car is an analogy for setting goals of care. (A) A hopeful and unrealistic driver wishes that nothing bad will happen on the road. This is in contrast to (B) the hopeful and realistic driver, who knows the importance of comfort measures and of being prepared for the trip ahead. Reprinted with permission from The University of Texas M. D. Anderson Cancer Center.

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GOALS OF CARE

Oncologists are in charge of discussing the goals of care with patients and their families. In the vast majority of cases, patients' goals are the cure or stabilization of the primary disease. This is quite understandable, even if these may not be the final outcomes in most cases. At the same time, it is important to help patients and families realize the concurrent goals of maximizing comfort along the cancer journey and being prepared for the challenges ahead. The use of a car analogy may help patients and their families understand the reasons for a referral to supportive/palliative care.

Figure 1 summarizes two different goals of the use of a car. Although the primary goal of the use of a car is to travel between places, a basic model without any comfort features would make the trip less enjoyable (Fig 1A). Furthermore, it would be unreasonable to assume that there is no chance of extreme weather, of rough roads, or of getting into an accident. Because these are real possibilities with negative effects on the primary goal, it is important to ensure that the car is equipped with both comfort and safety features (Fig 1B). These features do not denote a defeatist or hopeless attitude by the driver. Rather, they can reinforce enjoyment by improving the quality of the driving experience and providing peace of mind.

Cancer is a serious illness. The absence of any plans to manage physical and psychosocial distress and to prepare for the possibility of progressive disease (Fig 2A) should therefore be considered unreasonable denial rather than hopefulness. Figure 2B shows the role of concurrent supportive/palliative care in maximizing physical and emotional care, supporting patients through cancer therapies, enhancing their adherence to treatments, facilitating transitions of care, and preparing patients and their families for the challenges ahead.

Early introduction of supportive/palliative care might provide patients with better physical and emotional symptom control, allowing them to make informed decisions with less distress. The supportive/palliative care team could work in conjunction with the oncologist to facilitate decision making by putting the effectiveness and the adverse effects of various cancer therapies in perspective, allowing patients to acquire the knowledge and freedom to select treatments consistent with their goals. At the end of life, the presence of supportive/palliative care might also help patients to avoid unnecessarily harmful therapies that have no chance of meeting their goals of care.¹⁸

INTEGRATED-CARE MODELS

Recognizing the benefits of concurrent oncologic care with supportive/palliative measures, the American Society of Clinical Oncology



Fig 2. (A) A hopeful and unrealistic patient focuses on cancer cure and life-prolongation measures, without paying attention to her symptoms and advance care needs. This results in unnecessary distress for patients and families. This is in contrasts to (B) a hopeful and realistic patient, who has the same goals for cancer control, but is better equipped to manage symptoms and prepared for crisis because of the concurrent use of supportive/palliative care. ER, emergency room, CPR, cardiopulmonary resuscitation, ICU, intensive care unit. Reprinted with permission from The University of Texas M. D. Anderson Cancer Center.

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Downloaded from jco.ascopubs.org on September 1, 2010. For personal use only. No other uses without permission. Copyright © 2010 American Society of Clinical Oncology. All rights reserved. recently stated its vision of integrating palliative care into the model and vision of comprehensive cancer care by 2020.²⁵ Figure 1 summarizes three practice models in which an oncologist can address the complex issues surrounding cancer management in conjunction with supportive/palliative care.

The evaluation of patients with cancer requires complex multidisciplinary interventions by the primary oncologist. Such interventions include confirming diagnosis through biopsy review; thorough staging with sophisticated imaging, laboratory testing, and interventional radiology; formulating a complex treatment plan between medical, radiation, and surgical oncology; implementing a treatment regimen; and monitoring for tumor response, treatment toxicities, and cancer-related complications. With an aging population and an increase in cancer incidence,²⁶ there is a growing demand for oncologists. It becomes increasingly difficult for the busy oncologist to keep up with the growing literature on both novel cancer therapeutics and supportive/palliative care and to address all patient concerns ranging from complex decision making about cancer treatments to advancedcare planning during the short clinic visits. This is likely going to become a bigger issue as the practice of oncology and supportive/ palliative care get more and more complex and specialized.

As illustrated in Figure 3A, the oncologist takes care of all the primary disease assessment and management as well as the supportive/palliative care needs. This model is frequently required in private practices and small communities, where supportive/palliative care consultants are unavailable. The advantage is that the patient receives all aspects of care from the same health care professional. The disadvantages include time constraints, limited palliative care training,²⁷ and a risk of burnout in the oncologist as a result of the need to assume all aspects of care.²⁸ To deliver high-quality supportive/palliative care under this model, oncologists need to receive extensive training in this area.

Figure 3B illustrates the congress approach. In this model, the primary oncologist refers the patient to multiple consultants, such as a pain specialist for pain and a psychiatrist for emotional distress. The role of supportive/palliative care is limited to addressing end-of-life issues. This model is an attempt to obtain interdisciplinary care; however, it can be extremely exhausting and expensive for the patient and family, and the model may even compromise patient care. Specifically, the lack of interaction among consulting specialists who are taking care of interconnected problems the same patient is having can result in conflicting messages, drug interactions, and aggravation of one problem while trying to resolve another.²⁹

Figure 3C summarizes the integrated-care approach between the primary specialist and the supportive/palliative care team. This approach allows the oncologist to focus primarily on the management of the cancer, whereas the supportive care team addresses the vast majority of physical and psychosocial concerns. This model includes consultation of other specialists for specific reasons, such as respirologists for interventional endoscopy aimed at relieving bronchial obstruction; however, the majority of problems can be managed by a single supportive/palliative care team, thereby simplifying the number of visits and reducing cost. Oncologists can take advantage of these established teams, which allow them to focus on the complex issues associated with management of cancer. Supportive/palliative care can be integrated into the collaborative model that exists among surgical, radiation, and medical oncologists as the fourth pillar of comprehen-



Fig 3. Conceptual model for integration of palliative and supportive care in oncology. (A) In the solo practice model, the oncologist attempts to take care of all patient-related issues. (B) In the congress practice model, the oncologist focuses on cancer assessment and treatment and refers the patient to various subspecialties for other concerns. (C) In the integrated-care model, the oncologist collaborates closely with the interdisciplinary supportive/palliative care team to provide comprehensive cancer care. Reprinted with permission from The University of Texas M. D. Anderson Cancer Center.

Downloaded from jco.ascopubs.org on September 1, 2010. For personal use only. No other uses without permission. Copyright © 2010 American Society of Clinical Oncology. All rights reserved. sive cancer care, supporting patients and their families alongside oncologists.³⁰

Although the solo practice model may be necessary or preferred in some cases, the patient, the family, and the oncologist are best served by taking advantage of the integrated approach. The congress approach is generally not recommended.

SUMMARY

Patients with advanced cancer frequently experience significant symptom burden and psychosocial distress. Palliative care has evolved as a discipline that addresses many of these concerns. Yet, palliative care referrals remain delayed as patients continue to focus on cancer treatments. Using a car analogy, we propose that the two seemingly opposing goals of care-receipt of cancer therapies and symptom management-can be addressed concurrently under an integratedcare model. To ensure high quality and early access to supportive/ palliative care services, oncologists need to be comfortable with the core competencies related to symptom management, psychosocial interventions, communication, and transition of care. For patients with severe distress, early referral to the interdisciplinary supportive/ palliative care team is recommended. Through better integration and education, oncologists and supportive/palliative care specialists can work together to minimize the burden of progressive cancer for patients like Tom.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

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