

# Virtual Mentor

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## ETHICS CASE

### **Integrating Palliative Care with Disease-Modifying Therapy**

Commentary by Craig D. Blinderman, MD

Mr. James had been a heavy smoker most of his life. At 76, he had moderately severe chronic obstructive pulmonary disease (COPD) and coronary artery disease, and he had been feeling weak and coughing for several months. When he began to cough up blood his son took him to the emergency room, where a chest x-ray showed a speculated 3-centimeter right upper lobe mass and enlarged mediastinal nodes. Mr. James was admitted to the hospital. A positron emission tomography (PET) scan showed both the mass and the nodes to be highly reactive. A needle biopsy of the mass showed poorly differentiated adenocarcinoma (non-small cell cancer) that was stage III-B.

Mr. James's tumor did not have any of the mutations that would have enabled him to be treated with targeted therapy, so he was offered standard chemotherapy with cisplatin and paclitaxel. After two rounds of chemotherapy he began to feel slightly better. He had more energy and was no longer coughing up blood. His three children and their families had been a constant source of support; everyone tried to be optimistic, hoping that a remission would last for many years. But within 2 months, Mr. James began to notice back pain.

His first follow-up computed tomography (CT) scan revealed that, despite the chemotherapy, the tumor mass in his right lung was larger and the cancer had metastasized to his ribs and spine. The oncology resident on Mr. James's care team, Dr. George, had the responsibility of delivering this news to Mr. James and his family. Dr. George was aware of studies that had found associations between early referral to palliative care services and improved quality of life.

So, when he met with Mr. James and his family, Dr. George explained that the cancer had metastasized to Mr. James's ribs and spine. He said that, if chemotherapy were to continue, different agents would be needed and that radiation was indicated for the areas of Mr. James's spine that showed evidence of cancer. Dr. George introduced palliative care by saying, "I would also like you to talk to the staff in our palliative care service."

"Wait, what?" exclaimed Mr. James's daughter. "We've barely started fighting this thing and you want us to give up? You want us to just let him die? To help him die faster?" Murmurs and exclamations from the family followed. "No. No way. We're not going to let them pull the plug, Pops. We're going to fight this, and we're going to win."

Dr. George was unsure of how to proceed. He believed the sooner palliative care measures were started, the better off Mr. James would be. At the same time he wanted to assure the family that he wasn't "giving up" on Mr. James.

### **Commentary**

This case addresses the common—and challenging—issue of when and how to bring up referral for palliative care services to patients with serious illnesses, such as class-IV heart failure, end-stage chronic obstructive pulmonary disease, or, in this case, advanced, incurable lung cancer.

Palliative care attends to the physical, emotional, and spiritual condition of patients and their families. Research has consistently shown that cancer patients experience high symptom burden (e.g., pain, lack of energy, difficulty sleeping) associated with poor quality of life [1, 2] and have significant psychological distress [3, 4]. Families of patients with cancer also experience a high degree of emotional and psychological distress [5]. It would, therefore, seem appropriate that care dedicated to the alleviation of patients' symptoms be integrated early in the disease course to decrease the level of suffering experienced by patients and their families.

While multiple studies have shown the benefits of palliative care services on symptom distress and quality of life, physicians may feel that merely mentioning the words "palliative care" to patients and families suggests that the patient's life is nearing its end, that palliative care hastens death, or that a referral to palliative care is a sign that we are "giving up" and the best we can hope to do is simply treat the patient's pain and symptoms. In addition, some physicians may believe that a referral to palliative care is only appropriate when "there is nothing more that we can do." This dichotomous construct—that the patient can receive *either* disease-modifying therapy *or* palliative care—is incorrect. Palliative care should be integrated with disease-modifying therapy, regardless of prognosis or the success (or failure) of disease-specific treatments.

The most important study to date demonstrating the benefits of palliative care in advanced lung cancer patients [6] has recently led the American Society of Clinical Oncology to update its guidelines—with a provisional recommendation that patients with metastatic or advanced cancer be offered concurrent palliative care and oncologic care starting at initial diagnosis [7]. In this landmark study by Temel et al., 151 patients with stage-III-B or -IV adenocarcinoma of the lung were randomly assigned to receive either standard oncologic treatment or standard oncologic treatment and outpatient palliative care visits initiated at the time of diagnosis. Patients who received early-intervention palliative care experienced better quality of life and lower rates of depression, and, despite receiving less "aggressive" end-of-life care (32.7 percent versus 53.6 percent,  $p=0.01$ ), survived longer than those assigned to usual care (11.6 months versus 8.9 months,  $p=0.02$ ).

In addition, patients who received early palliative care were less likely to be hospitalized (55 percent standard care arm, 38 percent palliative care arm) and less

likely to die in the hospital. They had increased referral to hospice, increased length of stay in hospice, and were less likely to receive chemotherapy close to death. Another study, using a retrospective statistical analysis on selected cohorts from large databases of Medicare beneficiaries with cancer and congestive heart failure, showed a similar survival benefit for patients who received hospice services. Patients enrolled in hospice had a mean survival of 29 days longer than patients who were not ( $P=0.08$ ) [8].

In my own clinical experience, palliative care services are most beneficial when they are integrated early in the disease course. Indeed, the coordination of care and collaborative relationships that result from early involvement of palliative care services positively impact the entire care team, as well as the patient and family.

So how can we improve referral to palliative care services while patients are receiving disease-modifying therapy? One strategy is to introduce palliative care services “as an extra layer of support” at the time of initial diagnosis of advanced cancer or other life-limiting condition (assuming an appropriate level of palliative care outpatient services is in place). Another strategy is to identify a set of criteria or “triggers” to alert the primary clinician that palliative care services should be offered as a matter of best medical practice when the patient is found to have a high symptom burden or difficulty coping with the diagnosis, prognosis, or treatment plan.

A self-administered screening tool to assess unmet palliative care needs and patient distress can be implemented at each visit. Appropriate tools for this function are the Edmonton Symptom Assessment System (ESAS), the Memorial Symptom Assessment Scale (MSAS), or a disease-specific quality of life measurement tool (e.g., FACT-L for lung cancer patients). A cutoff score suggesting significant distress or poor quality of life (e.g., rating 5 or more symptoms as being moderate to severe on the ESAS) can be identified prior to implementing such measurement tools, and a score above the cutoff score could trigger a referral to palliative care. The oncologist can then simply say the following: “Given the number and severity of symptoms you are experiencing, I would like to refer you to our palliative care service. They have the expertise to focus on improving your symptoms and can help you and your family best cope with all the stress of living with advanced cancer while I continue to find ways to treat the tumor.”

Indeed, the Center to Advance Palliative Care (CAPC) has led the way by providing a comprehensive definition of “palliative care” cognizant of the phrase’s connotations. Palliative, after all, is related to the Latin word *palliare*, “to cloak.” After testing it with focus groups, CAPC has offered the following definition, which may help both clinicians concerned about referring their patients to palliative care and patients and families, who may misunderstand what palliative care is and how it may be helpful to them:

Palliative Care is specialized medical care for people with serious illnesses. It is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support.

It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment [9].

This definition, which accurately characterizes the role of palliative care, is certainly far from “giving up,” and does not imply that “there is nothing more we can do.” Indeed, it provides the kind of medical attention patients and their families expect and deserve.

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