A 46-year-old insured white man presented to the emergency department (ED) of his hometown community hospital with breathlessness. Physical examination in the ED indicated that he had a collapsed lung, and an x-ray film confirmed that there was an abnormality on his right lung and bronchus. He was admitted to the hospital with follow-up tests confirming non–small cell lung cancer that had spread to his brain. His 2 college-aged daughters were living at home with him while they were attending school, and his 14-year-old son was living with his mother in a distant town. He had a full-time job working as a computer technical support specialist, which required regular travel to various universities and conferences.

TODAY’S USUAL CARE

The patient was visited by a medical oncologist and a radiation oncologist in his hospital room the morning after his admission. They described his non–small cell lung cancer diagnosis as stage IV and recommended whole-brain radiation therapy (WBRT) followed by chemotherapy. They also told him that he would likely receive thoracic (chest) radiation therapy later on.

See Invited Commentary at end of article

- He was fitted with a skull immobilizer and began daily WBRT. After his breathing was better stabilized, he was discharged home under his daughters’ care to continue radiation therapy as an outpatient for a number of weeks. He eventually also received targeted radiation therapy to his brain lesions using the hospital’s linear accelerator technology. Because he was too weak to drive, he and his children arranged his daily rides to and from the hospital for WBRT sessions, which took about an hour each day.

- After WBRT was finished, chemotherapy was initiated, with outpatient infusions every 3 weeks, each of which took between 4 and 6 hours. He tolerated the first line of chemotherapy fairly well but was extremely nauseated and fatigued, had hair and weight loss, felt short of breath, complained that food tasted metallic, and continuously worried about how his diagnosis was going to affect him, his children, and his job, which he loved.

- Despite the series of chemotherapy infusions, the patient and his family were distressed to learn that imaging studies showed that the cancer had spread to the other lung. A second line of chemotherapy with different drugs was recommended. He also reported increasing levels of pain; his medical oncologist prescribed pain medication to address it; however, there was little follow-up for pain relief. As the chemotherapy continued, his pain intensified, with little relief provided by the medication; however, he did not realize that he should tell his physician that he was still in pain. He was also experiencing increasing breathlessness, which made him very anxious and worried his children. The pain medication also caused constipation, which made him uncomfortable and unable to sleep.

- The cancer continued to spread into his liver and bones, and his pain wors-
en. The oncology team recommended trying a third line of chemotherapy that would require limiting his exposure to sun. After much difficult deliberation at home, he and his family decided that he should stop chemotherapy and instead take the summer beach vacation that they had long planned. The physicians equipped him with a carload of oxygen tanks and more of the same pain medication that was providing little relief and causing digestive problems.

- He got to the beach in a wheelchair the first morning of vacation but spent most of his time indoors, uncomfortable, with pain, breathlessness, and a feeling of agitation. His children were distressed because they were unable to make him comfortable, and they were scared because his breathing seemed to be getting more difficult and his pain was getting even worse. He was unable to walk and barely able to talk with them. They decided that they needed to cut the vacation short and bring him back home.
- On their return, his daughters took a leave of absence from school to care for him. On 2 occasions, his symptoms became so severe that they had to take him to the ED. On the first ED visit, he was admitted to the hospital for treatment of an impacted bowel, which had resulted from adverse effects of his pain medication. On the second ED visit, about 1 week later, he was again admitted with severe pain and breathlessness.
- He underwent several extensive and uncomfortable imaging studies of his chest and head as an inpatient, all of which confirmed that the cancer had spread throughout his body. He died 2 days later in the hospital while awaiting a hospice consultation, just 3 days shy of his daughter’s 21st birthday. His family was left feeling abandoned by the health care system and by his physicians; his children were depressed and struggled in their efforts to return to school; and they were angry about the horrific suffering their father had to endure and they had to watch, reporting that they felt helpless and powerless at every point and that the system and the physicians had let them down.

A PREFERRED PATIENT-CENTERED SCENARIO: ADDING EARLY PALLIATIVE CARE

As part of the meeting that the patient had with the oncologists, and after cancer treatment options were discussed, the physicians also recommended a consultation with a palliative care specialist, a physician who specializes in helping patients and their families address quality-of-life issues. Based on that discussion, the medical oncologist requested a consultation for the patient with the hospital’s palliative care team, which included a board-certified palliative care physician, a nurse, and a social worker.

- After the patient’s first radiation treatment, the palliative care physician and nurse met him and his daughters in the hospital room. They explained that their job is to help the oncologists and others on the health care team keep him feeling as well as possible during and after his treatment, to listen to and address any concerns that he or his family might have, and to help align treatments with what is most important to them.
- During that conversation, they learned that the patient’s extended family had been going to the same summer beach vacation spot every year for the past 10 years and that he had been looking forward to attending a work conference in a few weeks in a nearby town. They also learned that he was very concerned about his children and what his cancer would mean for them. His daughters expressed similar concerns to the nurse but did not want to worry their father because they felt that he really needed to focus on fighting his illness. They were also worried about the impact that their father’s illness would have on their younger brother, who lived far away.
- The palliative care physician documented these quality-of-life concerns in the patient’s medical record, and together they discussed and identified what was most important to the patient and his family regarding the care that he would receive in the hospital and after he left, with specific discussion about helping reduce his breathlessness and resolving anxiety, as well as relieving any pain or other problems he might experience as radiation therapy continued and chemotherapy started later.
- Based on the consultation and before the patient’s hospital discharge, the palliative care team’s nurse and social worker had followed-up meetings with him and his daughters to explain how to use the pain medications that were prescribed and the accompanying medication that he would need to reduce their adverse effects. They also provided a number of what if questions that the girls had put together.
- The palliative care team worked with the oncologist to prescribe pain medication. The patient and his family learned how to use the medication so that it would effectively relieve his pain; he also learned how to prevent constipation using the other medication that he had prescribed. With his daughters’ help, he was pleased to report that he felt well enough to make a brief appearance at the work conference he had looked forward to so he could see his long-time colleagues, who were also friends, as he had not been able to return to work since his diagnosis.
- Immediately after hearing the difficult news from his oncologist that the cancer was not responding to the second line of chemotherapy, the patient and his children met with the palliative care physician. Together, they reviewed what the oncologist had said about the evidence regarding the prospects of third-line chemotherapy stopping the cancer’s spread, and, after considering the tradeoffs, the family decided instead to focus on making the patient comfortable enough to have one more vacation with his whole family at the beach. The team members adjusted his medications to address the breakthrough pain he had started to experience; they also prescribed medication to address his nausea and provided contact information for colleagues at a clinic near the beach where the family was going to stay.
When It’s the Right Care, More Is Better

The front page of the Wall Street Journal reports that, according to a randomized clinical trial, a new drug, palliatosin, when given to patients with metastatic non-small cell lung cancer, like the patient described by Kirch, reduces depression, improves quality of life, and, as emblazoned in the headline, lengthens life by 2½ months. Based on the results of this trial, the stock price for the maker of palliatosin rises sharply. Word spreads like wildfire among patients, driving intense demand for palliatosin. The manufacturer struggles to maintain adequate supplies. Palliatosin is hailed as a major breakthrough in cancer care. Although it costs $2000 a month and was tested only in patients with incurable lung cancer, physicians prescribe palliatosin to patients with all types of cancer at all stages based on its impressive impact and complete lack of adverse effects.

Unfortunately, the above description is fiction and palliatosin does not exist. If it did, all patients with cancer would ask for it, and most would get it. While palliatosin is not real, the outcomes are fact and, rather than resulting from a made up chemical compound, they derive from a real intervention consisting of experts in palliative care. This team achieved dramatic results and profoundly changed the course of care and quality of life for the patients described by Kirch and Meier in this issue of the Archives. As would be expected for rigorously designed research, the results of the randomized trial described above were reported first in the New England Journal of Medicine before being picked up by the Wall Street Journal and the New York Times.

With the addition of palliative care, Kirch’s patient experienced better pain control with fewer adverse effects, achieved a better quality of life, and, despite receiving less chemotherapy, lived longer. In fact, with the help of palliative care, he enjoyed a beach vacation with his family and lived long enough to celebrate his daughter’s 21st birthday. Meier’s patient experienced similar benefits. After 63 days in the hospital, withdrawn and combative, and enduring painful dressing changes, she found comfort, pain relief, and meaningful interactions with her family and was able to return to her original nursing home. Her nurses experienced relief from the distress of feeling like they were hurting her with every dressing change.

The addition of palliative care to the care of these patients had an impressive positive impact. However, it is equally impressive that an intervention focused on the patients also had such a positive effect on their loved ones. The children of Kirch’s patient received bereavement care after he died to help them adjust to their new life and return to school. They reported high satisfaction with the care that he received and gratitude for the time that they enjoyed with him in the last months of his life. Meier’s patient’s son experienced the warm glow that arose when his mother was able to recognize him and smile. Studies show that communication to understand and ensure that care aligns with patient preferences reduces depression and complicated grief in loved ones after the patient dies. Also, Meier’s patient’s nurses were no longer distressed, and the chief executive officer of her hospital had the pleasure of reading a letter from her family expressing gratitude for the palliative care that she received.

Palliative care also benefits our health care system and society. Each year, 27% of Medicare expenditures are used for the 5% of people who die. While we should expect to use...