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The Lake Wobegon Effect: Are All Cancer Patients above Average?

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Context: When elderly patients face a terminal illness such as lung cancer, most are unaware that what we term in this article "the Lake Wobegon effect" taints the treatment advice imparted to them by their oncologists. In framing treatment plans, cancer specialists tend to intimate that elderly patients are like the children living in Garrison Keillor's mythical Lake Wobegon: above average and thus likely to exceed expectations. In this article, we use the story of our mother's death from lung cancer to investigate the consequences of elderly people's inability to reconcile the grave reality of their illness with the overly optimistic predictions of their physicians.

Methods: In this narrative analysis, we examine the routine treatment of elderly, terminally ill cancer patients through alternating lenses: the lens of a historian of medicine who also teaches ethics to medical students and the lens of an actuary who is able to assess physicians' claims for the outcome of medical treatments.

Findings: We recognize that a desire to instill hope in patients shapes physicians' messages. We argue, however, that the automatic optimism conveyed to elderly, dying patients by cancer specialists prompts those patients to choose treatment that is ineffective and debilitating. Rather than primarily prolong life, treatments most notably diminish patients' quality of life, weaken the ability of patients and their families to prepare for their deaths, and contribute significantly to the unsustainable costs of the U.S. health care system.

Conclusions: The case described in this article suggests how physicians can better help elderly, terminally ill patients make medical decisions that are less damaging to them and less costly to the health care system.

Keywords: end-of-life care, hospice, NSCLC treatment, physician/patient communication.

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Nancy Wolf, an artist especially skilled at needlepoint, a retired medical records administrator, a wife, a mother of four, and a grandmother of two, died of lung cancer on June 15, 2010, at age eighty.

Her children—Jackie, Glenn, Kevin, and Rob—first learned of her illness on March 17, 2009, when she phoned each in turn to report that during her semiannual physical exam, Dr. P, her primary care physician, had ordered a chest X-ray because she had not had one in several years. The happenstance X-ray—not recommended for screening purposes by the U.S. Preventive Services Task Force, as discussed later in this article—revealed two masses on her upper left lung. Nancy soon learned that she had non-small-cell lung cancer (NSCLC). Physicians staged the cancer at IIB, due to the apparent confinement of the primary tumor to one lobe of the lung, with a secondary tumor nearby. The diagnosis led to more than a year of fruitless treatments.

Nancy had always expressed keen interest in her own medical history as well as the medical histories of family and friends. The inside front cover of her 2010 calendar diary, where she had inscribed a numbered list of personal medical events, reflected this fascination. The events appeared in no particular order: the first was a colonoscopy on November 3, 2006; the second was the removal of a cataract on July 9, 2001; the ninth was a torn medial meniscus on April 2, 2008. Her lung cancer treatments would soon merit a separate list.

In describing her initial diagnosis, Nancy felt lucky. She wrote in her diary, "I'm in good spirits & happy cancer was found & nothing had spread outside the lungs." If she had to have lung cancer, she thought Dr. P's thorough physical provided her with a likely good outcome. She was old enough to remember the once ubiquitous slogan of the American Society for the Control of Cancer: "In early treatment lies the hope of cure" (Leopold 1999).

In contrast, Dr. P did not view his finding as fortunate. When Nancy called Jackie to relay Dr. P's discovery, Nancy described what she considered his overwrought reaction. He told her how sorry he was. He reminded her that she'd had a wonderful life. Nancy laughed as she recalled his words, telling Jackie, "He acted like I'm dying."

During the course of her fifteen-month illness, Dr. P was the only physician to suggest, in a way that Nancy understood, that she had a terminal illness. At that particular juncture, however, she dismissed

his message. The diagnosis was unexpected. She felt fine. She had no symptoms. Over the next several months, Dr. P needed to take a more active role in Nancy's care, focusing on compassionate persistence in discussing her wishes for end-of-life treatment (Klabunde et al. 2009; Mack and Smith 2012). His role as Nancy's primary care physician, however, was about to be supplanted by an oncologist and a radiation oncologist.

Although Nancy did not understand the seriousness of her diagnosis, her children did. They had varied medical backgrounds as a historian of medicine (Jackie); an insurance executive specializing in fraud, including health scams (Glenn); an actuary with expertise in health care benefits and costs (Kevin); and a journalist who once worked the health beat (Rob). Cursory research informed them that if their mother's cancer were to metastasize (a likelihood), her median life expectancy would be eight to eleven months. Thirty to 45 percent of patients with advanced NSCLC who are treated with platinum-based chemotherapy combinations survive for one year; 10 to 20 percent survive for two years (Soon et al. 2009).

Getting on the Treatment Treadmill

On March 19, Nancy met with Dr. S, a thoracic surgeon. Herb, her husband of fifty-nine years, accompanied her, as did Kevin, who lived nearby, and Jackie, who left her home in another state at 4 A.M. in order to join her mother, father, and brother for the 1 P.M. appointment. At that appointment, and at every appointment he attended during his mother's illness, Kevin took detailed notes and digitally recorded the conversation so that he could share with his three siblings, who all lived out of town, the identical information that doctors conveyed to him, Nancy, and Herb.

Dr. S told Nancy that she was one of the 25 percent of lung cancer patients he could help, as her tumors appeared to be isolated in or near her upper left lung. Within days, Nancy learned that the PET scan ordered by Dr. S confirmed his suspicion that her tumors were confined to the left lung area.

On April 8, Dr. S removed the upper lobe of Nancy's left lung and tested a lymph node near the primary tumor. The node was cancer

free. In late May 2009, Nancy had a follow-up chest X-ray and appointment with Dr. S. He told her that the cancer appeared to be gone.

On June 3, Nancy met with Dr. O1, an oncologist, to discuss follow-up treatment. Over the next twelve months, Dr. O1 would be the primary physician treating Nancy's cancer. At their first appointment, he told her that although studies showed that patients with stage I NSCLC did not benefit from chemotherapy, patients like Nancy, with stage IIB NSCLC, did seem to benefit. He also informed her that although only 50 percent of stage IIB patients who eschewed chemotherapy survived for five years, 60 to 65 percent who did have chemotherapy survived for that long.

Herb and Kevin, both actuaries and present at the appointment, asked Dr. O1 if Nancy's age, then seventy-nine, would make it harder for her to weather chemotherapy. In response, Dr. O1 admitted that most NSCLC research subjects were younger than Nancy. He then revised downward his five-year-survival-without-chemotherapy estimate, to below 50 percent. When the two actuaries pointed out that as a seventy-nine-year-old, Nancy's prognosis was also likely bleaker than studies indicated even *with* chemotherapy, Dr. O1 offered anecdotal evidence supporting treatment. He noted that a current patient, now seventy-seven, was still alive one year after four rounds of chemotherapy.

The opportunity for Nancy to understand her illness and make fully informed medical decisions in conjunction with her physicians and family, afforded by Dr. P, had now been thwarted by Dr. O1, who spoke only of survival rates (Kiely, Stockler, and Tattersall 2011; Smith et al. 2011; Smith and Longo 2012; Weeks et al. 2012). Chasing cures soon became the focus of Nancy's life.

Chemotherapy following a cancer diagnosis is so routine in the United States that neither Nancy, Herb, nor Kevin aggressively questioned Dr. O1's suggestion that Nancy undergo three to four intravenous treatments consisting mainly of carboplatin, a drug that Dr. O1 explained was as effective as the more commonly used cisplatin, but with fewer side effects.

As everyone left his office, Dr. O1 explicitly stated that undergoing chemotherapy was Nancy's decision to make (digital recording, June 3, 2009). The evidence he provided in support of chemotherapy, however, contributed more to Nancy's uncertainty than to her ability to make a sound decision.

Treatment Studies for Patients with Early-Stage NSCLC

Dr. O1's lack of clarity on the efficacy of treatment reflects the ambiguity of cancer studies. Results differ depending on patients' age, gender, comorbidities, and cancer stage. As Dr. O1 acknowledged after questioning, most cancer studies use research subjects who are considerably younger than the average cancer patient. While the mean age for all lung cancer patients is 70.6 years (Altekruse et al. 2010), the median age of research subjects in the major studies examining the effectiveness of chemotherapy for early-stage NSCLC—LACE (Pignon et al. 2008), ANITA (Douillard et al. 2006), ALPI (Scagliotti et al. 2003), IALT (Arriagada et al. 2004), and Big Lung Trial (Waller et al. 2004)—is about sixty.

Yet age, in particular, affects outcome. According to national SEER data—as opposed to the statistics gathered in the small studies cited by Dr. O1—five-year survival rates are 20.6 percent for patients who are under sixty-five at diagnosis and 12.3 percent for patients over seventy-five (Altekruse et al. 2010). And contrary to Dr. O1's claim, when compared with patients who do not have chemotherapy, very few additional research subjects treated with cisplatin-based chemotherapy survive longer than five years, despite their younger age: only 5.4 percent in LACE, 1 percent in ALPI, 4.1 percent in IALT, and 8.6 percent in ANITA. Big Lung Trial had the most sobering statistics: chemotherapy recipients had worse survival outcomes (-5%) than the placebo group.

For elderly NSCLC patients in particular, there is scant evidence to support any chemotherapy. Chemotherapy provides no survival improvement for those aged sixty-five to sixty-nine. Among those seventy or older, only the few who live at least three years after diagnosis see a slight improvement in survival rate: 45 percent of those who have chemotherapy versus 40 percent of those who do not, significantly fewer than Dr. O1's claim of 60 to 65 percent who have chemotherapy. And while only about 5 percent of additional research subjects who are treated with chemotherapy actually survive for at least five years after treatment, 30 percent or more suffer levels of toxicity that are severe and/or permanently disabling (Fruh et al. 2008). Indeed, 1 to 3 percent of research subjects die not from their illness but from the effects of chemotherapy (Fruh et al. 2008; Pignon et al. 2008; Waller et al. 2004). Studies include these deaths in their compilation of overall survival rates.

These studies overlook gender, too. Although nationally only 52 percent of lung cancer patients are male (Altekruse et al. 2010), men comprise 80 percent or more of the research subjects. In the last thirty years, the medical community has learned that underrepresenting females in clinical trials ensures ignorance of how an array of treatments, including chemotherapy, affects women (Merton 1993). Dr. O1 also failed to consider the normal life expectancy of a seventy-nine-year-old is about 45 percent that of a sixty-year-old (CDC 2010), the median age of research subjects in the typical early-stage NSCLC study. When discussing prognosis with Nancy, Dr. O1 did not consider her reduced life expectancy, nor do the vast majority of chemotherapy studies. An exception is LACE by Age (Fruh et al. 2008).

In short, the population followed in the studies referenced by Dr. O1 was not relevant to Nancy, particularly in light of her age and gender (Fruh et al. 2008). Yet Dr. O1, as most physicians do, implied that the complex conclusions of the studies apply to everyone. Consequently, the results of cancer studies, when filtered through oncologists to patients, are not only confusing to the very patients who must make informed decisions based on what they learn from their doctors but often inapplicable to their cases. After talking to Dr. O1, Nancy interpreted his overly optimistic statistics to mean that she was similar to a child living in Garrison Keillor's mythical Lake Wobegon—above average—and thus could expect to see the best possible results from treatment.

Decisions, Decisions

In early June 2009, while Nancy was still contemplating chemotherapy, the entire family traveled from different parts of the country to Jackie's home to celebrate Jackie's daughter's graduation from high school. During the visit, Jackie invited her mother to be a guest on the radio show, focusing on assorted topics in health and medicine, that she hosts each month for the local National Public Radio station.

On the show, Nancy described her illness and the decisions she had yet to make about treatment. Deciding to have lung surgery was easy, she said, because it had been "clear the cancer had not spread to other organs yet." But because one of the tumors removed by Dr. S had been close to a lymph node, he feared node involvement. So, Nancy explained, she was seeing an oncologist, "a very charming, nice, intelligent guy," who

told her she was a good candidate for chemotherapy due to her youthful energy and lack of comorbidities. She explained that her oncologist had assured her that choosing to forgo chemotherapy was also a reasonable option because "I can't cure you."

Despite repeating on the air Dr. O1's verbatim assessment of his inability to cure her illness, Nancy's family soon realized she did not understand the meaning of his words. In the coming months she depicted as curative each of the treatments that Dr. O1 recommended. At one point, she described chemotherapy as able to "put my cancer in stasis," as if metastatic lung cancer could be rendered a treatable, chronic condition. After the cancer had metastasized to her brain and she decided to undergo whole brain radiation therapy (WBRT), she claimed WBRT would "make my brain inhospitable to cancer," as if radiation could render entire organ systems cancer-free zones. In light of her doctors' descriptions of "survival rates," coupled with their continual offers of treatments, Nancy interpreted every proffered treatment as a potential cure, a means to "survive," despite Dr. O1's I-can't-cure-you message.

On the radio show, though, Nancy seemed to be leaning toward rejecting chemotherapy. She thought that because her cancer had been detected early and removed, it now was completely gone. "Maybe I can [still] live twenty years and it won't recur," she said.

Upon returning home, however, Nancy abandoned her inclination to forgo chemotherapy after a friend convinced her to seek a second opinion about prognosis and treatment. Accompanied by Herb and Kevin, Nancy saw Dr. O2, another oncologist, on June 18. Attempting to gauge Nancy's health and strength, Dr. O2 asked Nancy, "What do you do all day?" She responded that she read, did needlepoint, took walks, and gardened. Dr. O2 was especially interested in Nancy's claim that she gardened. "On your knees, on the ground, doing your stuff? Not directing a gardener?" No, Nancy told her, she was the gardener. Dr. O2 was impressed by Nancy's vigor and then asked about her siblings. Were they still alive? Living independently? Nancy answered both questions affirmatively; her ninety-one-year-old sister and her eighty-seven-year-old brother were still alive and living independently. Learning that Nancy had older, fit siblings and that she, too, was energetic, Dr. O2 urged her to opt for chemotherapy. Nancy agreed she would be able to handle chemotherapy: "I'm seventy-nine chronologically but much younger physically."

In an easy-to-understand manner, Dr. O2 listed treatment options and described their side effects and outcomes. "If you get chemotherapy," she told Nancy, "you can decrease the risk very substantially in my eyes." She made a claim similar to Dr. O1's faulty assertion, that out of every one hundred, fourteen or fifteen additional people see a "survival benefit" after undergoing chemotherapy. "To me that's huge," she said. "Realize that for breast cancer we do chemotherapy for a 3 percent gain." She told Nancy, "If it's a question of some [chemo]therapy or no therapy, I'd rather you get some therapy." She also offered anecdotal evidence to support her recommendation. One of her patients, "a lovely woman" Nancy's age who had chemotherapy after being diagnosed with stage 1B lung cancer, was "doing really well . . . two years out" with "almost all of her symptoms . . . completely resolved" (digital recording, June 18, 2009).

As she talked, Dr. O2 performed a physical examination. During the exam, she thought she felt a mass above Nancy's collarbone. She recommended Nancy get a CT scan that day if it could be arranged. Kevin left to return to work; Nancy and Herb stayed at the hospital so Nancy could have the CT scan.

During a hastily arranged appointment later that afternoon, Dr. O2 relayed the bad news to Nancy and Herb: the scan had revealed a spot on Nancy's liver. Since Kevin had left several hours earlier, there is no recording of that second visit, and Herb cannot remember how Nancy reacted to the news. He recalls only that Dr. O2 suggested that Nancy undergo chemotherapy at the hospital where she had admitting privileges—almost an hour's drive from Nancy and Herb's home. Given the rigors of chemotherapy, neither of them ever considered traveling that distance to get the treatment.

Nancy did not see Dr. O2 again. Instead, she made another appointment with Dr. O1.

In response to the news from Dr. O2, Dr. O1 ordered two more CT scans on June 19, an MRI on June 24, and a PET scan on June 29. Dr. O1's news was even worse. The PET scan confirmed the liver mass and revealed two more tumors: one on Nancy's mediastinal lymph node and another midway down her spine (Nancy Wolf's medical record, June 29, 2009). He explained that the liver tumor had probably been there before her lung surgery but likely had been too small to appear on the presurgery scans (digital recording, June 30, 2009). For the first time, Nancy learned that a tumor is not visible on a scan until it consists of millions (in seeking a third opinion, another oncologist said billions) of cells.

Now, rather than repeat his assertion that it was up to Nancy to make her own decision about treatment, Dr. O1 spoke favorably about chemotherapy, specifically of his success with the pairing of two drugs: carboplatin and pemetrexed (Alimta). He advised that Nancy undergo four treatments, each three weeks apart. After the second treatment, he planned to order a CT scan to see if the liver tumor had decreased in size. He told her that chemotherapy reduced the tumors of one-third of patients (digital recording, June 30, 2009). Nancy decided to undergo the recommended treatment.

On July 30, a few hours before Nancy's second round of chemotherapy, Jackie phoned her mother. During that conversation, Jackie learned for the first time how little her mother understood about the nature of her illness. In describing the travails of a childhood friend who also had lung cancer, Nancy ended the story of her friend's illness with the observation, "But her cancer is completely different from mine." Jackie recalled the rest of that conversation:

"Oh?" Jackie asked. "Her cancer isn't non-small-cell?"

"No, it is."

Puzzled, Jackie pressed her mother. "So how is it different?"

Nancy responded impatiently, "*Her* cancer is terminal."

Jackie was stunned. She said nothing, unsure of how to contradict her mother's interpretation of doctors' messages.

Effect of Chemotherapy on Advanced-Stage NSCLC

Nancy's confusion should not have been surprising. After Dr. O2 found the tumor on her liver, physicians stopped alluding to long-term survival. They knew the likelihood of living beyond one year is significantly lower after lung cancer has metastasized. Yet Dr. O1 never explained this to Nancy, even though a seventy-nine-year-old white female with stage IV NSCLC faces, even after chemotherapy, at least thirteen times the probability of dying than standard mortality tables indicate (Goldberg et al. 2010).

In fact, the main difference between early- and advanced-stage NSCLC studies is that the former provide five-year survival rates and the latter, only one- and two-year survival rates. The median survival in advanced-stage studies using cisplatin combinations (a mix of drugs different

from the carboplatin/Alimta regimen that Nancy took) is 7.6 to 11.3 months from the start of chemotherapy; only between 7 and 24 percent of subjects survive two years (Bonomi et al. 2000; Hensing et al. 2003; Kubota et al. 2011; Sandler et al. 2000). Since Nancy's death, studies show that carboplatin/Alimta treatments have similar results: overall median survival is 9.3 to 10.3 months (Gervais et al. 2013; Zukin et al. 2013). As noted earlier, however, no matter what treatment she chose, Nancy's prognosis was even bleaker. In advanced-stage studies, research subjects with a median age between sixty-one and sixty-five (as opposed to a median age of sixty in early-stage studies) were still considerably younger than Nancy (for a notable exception, see Gervais et al. 2013).

Like all chemotherapy, the carboplatin/Alimta combination is a two-edged sword. Although in some instances it prolongs life, it also has serious side effects. Two to 4 percent of patients die from treatments (Gervais et al. 2013; Zukin et al. 2013). At least 40 percent suffer from nausea, vomiting, anemia, and/or low white blood cell and platelet counts. More than 30 percent require red blood cell or platelet transfusions (Grønberg et al. 2009).

Back on the Treatment Treadmill

Except for the effects of the carboplatin/Alimta, Nancy still felt fine. After her second treatment, Dr. O1 ordered two CT scans to assess the chemotherapy's effectiveness. The scans revealed no new tumor growth and a shrinkage of the existing tumors—good news. Dr. O1 told Nancy the chemotherapy was doing its job: "maintenance." Nancy interpreted this assessment to mean that her tumors had entered a form of stasis that could be "maintained," possibly indefinitely, via chemo and other treatments. Perhaps there was no cure for her illness, but the message heard by Nancy was that the treatment was working thus her illness was treatable.

Jackie, however, upon learning from her mother that "there is no cure for this, but the chemo is working," heard a different meaning. Jackie had just read an article in the *New York Times* explaining that when physicians meet with terminally ill patients, instead of explicitly soliciting their patients' wishes for end-of-life care, they customarily issue what they term a "warning shot." One example of a warning shot was to tell a patient "there are no established cures" for a particular

illness. Only a small minority of patients understood the meaning of this statement—that they would soon die. Most patients heard no such implication. Despite the ambiguity inherent in this tactic, physicians rationalize that the use of euphemistic phrases spares their patients news they prefer not to hear anyway (Hartocollis 2009).

On October 1, three weeks after her last chemotherapy treatment, Dr. O1 discussed with Nancy what to do next. He offered her two options: (1) wait for the tumors to grow larger and spread and then begin "maintenance chemotherapy" using Alimta or (2) start the "maintenance" immediately. According to Dr. O1, both options offered the same "overall survival." Nancy decided to wait.

Nancy still sought a cure, though, and asked Dr. O1 about radiation. Now that she thought the tumors could be indefinitely "maintained" in their present form, she asked, "Can't these spots be zapped with radiation to kill them?" Dr. O1 explained that while a radiation oncologist might be able to destroy a few tumors, there was no guarantee that the cancer had not already spread to other, unseen, locations. Besides, he explained, he wanted to use her liver tumor as "a benchmark" in diagnostic scans to ascertain how a particular treatment had affected tumor size (digital recording, October 1, 2009). Nancy decided to get another opinion. She did not want a benchmark growing in her body.

In late October she spoke with Dr. O3, another oncologist. While reiterating that a cure was unlikely, Dr. O3 suggested three possible drug avenues: Alimta ("But you've already had that" he observed); Taxotere ("It's a pretty effective drug . . . a little tougher than the chemo that you've had before"); or Tarceva, an oral medication intended for patients with advanced-stage lung or pancreatic cancers ("The odds of benefit are not very high," he said of the Tarceva, "[but] it sometimes works exceptionally well") (digital recording, October 21, 2009).

Dr. O3 knew that Nancy was seeing him primarily to talk about treating her cancer with radiation, and he agreed that it was another option: "There are some radiation oncologists that are looking at this idea of trying to hit the known spots to see whether you can sort of buy time that way, without having to take on the additional side effects of chemo and so on." He told Nancy that in her case, radiation might be appropriate if another PET scan confirmed five or fewer metastases. Nancy was heartened.

Dr. O3 described a theoretical radiation protocol if the scan proved favorable. "It seems reasonable to do the radiation option, do it and then

follow up with PET scans . . . follow up and then, at a later time, if something else shows up, then you open up your chemotherapy options again." Toward the end of the conversation, he mentioned that recent studies indicated that "maintenance Alimta," which Dr. O1 also had mentioned, could be helpful. "I'm just not sure that's necessarily better than doing nothing," he said in reference to the Alimta. "But also I'm more inclined to say do *something*" (digital recording, October 21, 2009).

Nancy had a PET scan on October 28 ordered by Dr. O1. She met with Dr. O1's assistant the next day to learn the results. The assistant told her that the scan showed not three but five tumors (on her liver, in her chest, and three on her spine). Although the news was not good, at least the five tumors met Dr. O3's criteria for considering radiation. Nancy asked the assistant about that possibility. The assistant recommended Nancy get an MRI to confirm the results of the PET scan (digital recording October 29, 2009).

On November 2, Nancy had two MRIs ordered by Dr. O1. When she met with him on November 5, he told her that the scans revealed three additional masses on her spine that the PET scan had not caught; now there were eight known tumors. Dr. O1 recommended that she begin taking Tarceva, the oral drug that Dr. O3 also had proposed as a possible treatment (digital recording, November 5, 2009).

Nancy was disappointed and undecided. Adding to her uncertainty was the fact that except for the side effects of treatment, she remained asymptomatic. She still was fixated on radiation as a cure, though, so Dr. O1 arranged an appointment with Dr. R, a radiation oncologist. Nancy hoped that Dr. R would at least agree to radiate the two largest masses in her body. But Dr. R agreed with Dr. O1 that unseen tumors might already be growing, so radiation would be useless at this point in her illness. He also explained that radiation could destroy bone marrow and thus interfere with the effectiveness of chemotherapy. Dr. R advised Nancy to pursue maintenance chemotherapy instead, calling it "whole body treatment," as opposed to site-specific radiation (digital recording, November 10, 2009).

Nancy had hoped that radiation could be used to destroy the known tumors and felt that five was an irrationally arbitrary number. Why were five tumors the threshold for radiation? Why not eight?

A few days after meeting with Dr. R, Nancy decided to try the Tarceva, an expensive drug, particularly for patients with standard Medicare Part

D drug benefits. Between mid-November 2009 and mid-March 2010, Tarceva cost Nancy and Herb $8,096 out of pocket. Adding Medicare's contribution, payments for the drug totaled $15,404.

While on Tarceva, Nancy continued to have periodic scans ordered by Dr. O1, either CTs or MRIs, every three to eight weeks to monitor changes in her tumors. Initially, tumors were unchanged. Then the tumor on her liver grew slightly, followed by an increase in the number of tumors on her spine.

Erlotinib (Tarceva) Trials

Tarceva targets an epidermal growth factor receptor (EGFR), a tumor promoter found in some patients with NSCLC. Studies of the drug indicate mixed results, likely because not all NSCLC patients have the receptor (Reck et al. 2010). Nancy's medical records indicate that although Dr. O1 did discuss "genotyping her primary tumor for the EGFR mutation status," nothing further in her medical record indicates that this was ever done.

Compared with chemotherapy alone, Tarceva demonstrates no benefit when combined with chemotherapy (Gatzemeier et al. 2007) except, perhaps, for patients who have never smoked (Herbst et al. 2005). Nancy, however, smoked for thirty-five years. She quit smoking in the early 1980s. When Tarceva is administered as a stand-alone drug, some people in some populations (Asians, females, and patients who react to Tarceva with a particularly bad rash) show a slight benefit, in that the cancer does not worsen for at least some amount of time while Tarceva is being taken (Comis 2005; Herbst et al. 2005; Reck et al. 2010; Shepherd et al. 2005). One study indicates that patients taking Tarceva live an average two months longer (6.7 as opposed to 4.7 months) than patients receiving a placebo. Thirty-one percent of the patients on Tarceva were still alive after one year versus 22 percent receiving a placebo (Shepherd et al. 2005).

Tarceva's potential side effects are significant: rash; diarrhea; liver and kidney damage; holes in the stomach, small intestine, and large bowel; skin blistering; lung injuries; and death (Genentech 2013). More patients over seventy taking Tarceva have severe, disabling, and fatal toxicities than do patients under seventy—35 versus 18 percent (Wheatley-Price et al. 2008). By mid-January 2010, Nancy suffered

from a facial rash, fatigue, loss of appetite, and diarrhea so severe that she could not get to the bathroom in time.

Nancy's First Non-Iatrogenic Symptoms

Nancy began to complain of pain in her shoulders and neck. On March 10, 2010 she had two CT scans showing two compression fractures of her spine. Two MRIs on March 16 revealed seven spots on her brain (Nancy Wolf's medical record, March 16, 2010). She stopped taking Tarceva.

Now Dr. O1 told Nancy that radiation was an appropriate treatment. He suggested that she see Dr. R again to discuss radiating the brain tumors to keep them from spreading.

Instead of radiation, however, Nancy's husband and children wanted her to consider hospice care. Jackie had long admired a large banner honoring National Hospice Week, displayed each year in the town where she lived. The banner read, "Hospice—for the love of life." Jackie tried to convey that message to her mother. "Hospice isn't about dying, Mom; it's about living to the fullest and best." But Nancy thought hospice meant "giving up," though she did agree to talk to a hospice nurse.

Nancy made another appointment with Dr. R for March 18. Kevin scheduled an appointment with a hospice nurse for later that same day.

Accompanied by Herb and Kevin, who recorded the visit as had become his custom, Nancy complained to Dr. R about an ache on the left side of her neck, a burning sensation on her left shoulder, and her tongue not working properly when she talked. Dr. R recommended whole brain radiation therapy (WBRT). He explained that the blood-brain barrier prohibited chemotherapy from entering the brain, hence the need for radiation once cancer had metastasized to the brain. Kevin asked whether the recommended WBRT was curative or palliative. Dr. R responded, "The idea is that . . . a tiny dot on the brain can have devastating, life-changing problems . . . if we did nothing there would be big trouble in three months." Later in the conversation, he claimed that radiating the neck in addition to the brain would reduce Nancy's neck pain.

Dr. R assured Nancy that WBRT would "double or triple the time before it [the brain metastases] causes problems." He told her that after undergoing brain radiation therapy, "there's something like 20 to 25 percent of people who do very well two years down the road with the

brain." He added it was "very unlikely" that radiating her brain would cause serious side effects.

Kevin mentioned to Dr. R that Nancy had an appointment later that morning with a hospice nurse to discuss an alternative to additional treatment. On hearing this news, Dr. R raised his voice insistently. "Hospice and radiation therapy do not go together." If Nancy chose hospice, he explained, Medicare would not pay for the brain radiation that he recommended. Instead, hospice would provide only "pain meds . . . and do nothing and let the tumor grow . . . but then you'll have to take more pain meds and more pain meds." He compared the side effects of any pain medication provided by hospice unfavorably with the side effects of radiation treatment: "Many times people say, let's skip the radiation. The downside is then you're stuck on the management . . . [being] pain meds, which has side effects. Radiation has temporary side effects, maybe a little scratchy throat."

Although Dr. R's characterization of hospice care scared Nancy and thus predisposed her to close her ears to the hospice nurse she would meet later that day, he was correct about Medicare payments to hospice providers. Medicare reimburses hospice a fixed daily rate. This type of reimbursement plan, as Dr. R noted, will not cover radiation therapy. By definition, hospice provides only palliative care to patients who doctors expect will live six months or less. From mid-April to mid-June 2010, when Nancy finally did avail herself of hospice care, the Medicare reimbursement rates for hospice were $153 for home care on a typical day, $890 daily for home care during a crisis, and $636 for daily inpatient care in the event of symptoms that could not be handled at home (MedPAC and Centers for Medicare & Medicaid Services 2009).

After listening to Dr. R, though, hospice was off the table for the time being as far as Nancy was concerned. Instead of seriously considering that option, as her husband and children hoped she would, Nancy heard the implied promise in Dr. R's use of the phrases "double or triple the time" and "two years down the road." She asked Dr. R at one point in the conversation, "If we do this and then you don't do it forever and it keeps coming back, is there a point of no return? Or just by doing the whole brain, maybe it doesn't come back as often? Is that what you're thinking? Or what? How does it work?" Dr. R. responded to her series of questions with a question of his own—"What if we did nothing?"—and then provided his own answer by painting a grim picture of Nancy

waking up one morning unable to speak or move. He told her, "Those types of things are not, will not, be treated by hospice."

Toward the end of the conversation, Dr. R observed that the spots on Nancy's brain were "little, little dots throughout" that would likely respond well to radiation. Although other patients sometimes presented with a "worrisome spot" needing follow-up with a gamma knife, there was a "reasonable chance" that thirteen WBRT treatments would be all Nancy needed. But she had to decide immediately what to do. "We don't want to wait," he told her. "Once something's in the brain, it becomes kind of a hurry up, hurry up."

Throughout their hour-long appointment, Dr. R delivered a stream of contradictory messages. At one point he said, "If [Dr. O1] had the magic drug to prevent the next fire from popping up, then we wouldn't even be talking about hospice." But a minute later he told Nancy, "I think these thirteen treatments, based on the size [of the brain metastases], very likely that's all you'll need." Nancy inferred the possibility of a cure in Dr. R's supposition that there was a "reasonable chance" thirteen treatments would be all she would need. In referring to what might happen after she completed the course of WBRT, she said hopefully, "Maybe I won't have to have anymore [treatments]. Who knows? Who knows what's going to happen?"

Kevin was frustrated. He asked Dr. R to provide studies demonstrating the efficacy of WBRT. Dr. R promised to fax him some studies. Kevin handed him his business card.

Before leaving Dr. R's office, Nancy scheduled the series of radiation treatments.

Nancy's official medical record of the visit with Dr. R contains only generic notes that read, in part,

> Assessment and recommendation: Whole brain radiotherapy with palliative intent is indicated. . . . The rationale, goals, technical factors, side effects and alternative options have been discussed with the patient and family. The patient has agreed to proceed with a treatment plan of 3250 cGy to the whole brain and spine from C5-T4 in 13 fractions.

This notation in Nancy's medical record does not describe what actually transpired at the visit. Although Dr. R spent an hour with Nancy, Herb, and Kevin, he provided them with almost no information about the treatment he was offering. He never explicitly stated that the treat-

ment was only palliative. Instead, he implied that WBRT would stave off the spreading tumors and their effects. He did not mention side effects. To the contrary, he stated there would likely be no side effects other than temporary hair loss and a passing scratchy throat, nor did he state or explain the actual treatment he proposed: "3250 cGy to the whole brain and spine." And not until Kevin mentioned that his mother had an appointment later that day with a hospice nurse, did Dr. R offer any alternative to radiation.

Nancy, Herb, and Kevin went from Dr. R's office to Nancy and Herb's home to meet with the hospice nurse. The nurse explained that hospice becomes the patient's 911 system, handling all medical emergencies. For fixed daily fees paid by Medicare, hospice provides medical equipment (such as oxygen), medications to ease discomfort, and nurses' visits so patients can remain comfortably at home. After the appointment with Dr. R, however, Nancy had already made up her mind to reject hospice care, at least until the radiation treatments were completed.

By the end of the next day, the studies that Dr. R had promised had not arrived, so Kevin called his office. In response, instead of studies demonstrating the efficacy of WBRT, someone faxed Kevin four pages from the National Comprehensive Cancer Network's 2010 edition of *Practice Guidelines in Oncology*. Kevin—who had asked Dr. R for information about WBRT's outcomes, adverse effects, and survival rates—was flummoxed.

By March 23, the day after Nancy began radiation treatments, Kevin still had not received any of the promised studies showing the effectiveness of WBRT for patients with brain metastases due to NSCLC. He called Dr. R's office again. Dr. R was annoyed, reminding Kevin that Nancy had already made her decision. She had even begun treatment. Why was it still necessary to provide studies? Wasn't it enough that Dr. O1 had recommended him and Nancy had agreed to the treatments? According to Kevin, Dr. R said to him, "You really want me to dig out twenty-year-old studies? Why don't you just Google it?"

Kevin explained that he respected his mother's right to make her own medical decisions but that thus far, none of the recommended treatments—not the lung surgery, not the Alimta/carboplatin, not the Tarceva—had deterred the course of his mother's illness. The tumors kept growing and spreading even as the treatments caused debilitating side effects. So why should Nancy or her family rely solely on Dr. R's assurance that radiation would help?

The next day Jackie called her mother. During their conversation, Nancy said that the day before Dr. R had made an unusual appearance after her daily radiation treatment to express his concern that her children were undermining her treatment with their negativity. Nancy—who was unaware of Kevin's conversation with Dr. R and, indeed, never did learn of it—told Jackie that she had assured Dr. R that she would not listen to her children. She had faith in his expertise.

WBRT: What the Studies Show

WBRT has become the standard treatment for patients who have one or more metastatic brain tumors. In the aftermath of the treatment, however, few patients experience even a partial remission. Researchers have noted that patients who develop brain metastases as a result of NSCLC have an even worse prognosis than do patients with other primary malignancies and that their life expectancy, even with WBRT, can often be measured in weeks (Barton 2008). The less than 8 percent of patients who survive for more than two years after WBRT (Hall et al. 2000) commonly endure the long-term, debilitating side effects associated with radiation poisoning, such as brain atrophy; necrosis; endocrine dysfunction; loss of control over voluntary movements, with accompanying falls and broken bones; speech problems; and dementia (Antoniou et al. 2005; DeAngelis, Delattre, and Posner 1989).

Most WBRT trials are retrospective, and none compare WBRT-treated patients with those who refused the treatment. Instead, the studies compare patients receiving WBRT with those receiving WBRT plus another type of treatment, such as the attempted surgical removal of tumors or stereotactic radiosurgery (Li et al. 2000; Zabel et al. 2002). With or without additional treatments, median survival is typically less than one year.

The central irony of treating cancer with radiation, of course, is that exposure to too much radiation can cause cancer. An individual's average annual radiation exposure from natural sources is about 3.1 milliSieverts (mSv); no adverse effects have been discerned at this level of exposure. Cancers associated with high-dose exposure, defined as greater than 500 mSv, include leukemia, multiple myeloma, and cancers of the breast, bladder, colon, esophagus, liver, lung, ovary, and stomach (U.S. Nuclear Regulatory Commission 2011). After Nancy died, Kevin discovered that his mother's thirteen brain radiation treatments, "3250 cGy" or

32,500 mSv in total (plus 19,000 mSv to her neck and spine), were the equivalent of one million single-view chest X-rays. The WBRT and neck radiation together were the equivalent of 16,613 years of natural exposure to radiation delivered in less than three weeks (Smith-Bindman et al. 2009). In other words, WBRT exposed Nancy to sixty-five times cancer-causing levels to her brain and thirty-eight times cancer-causing levels to her neck.

The reason that oncologists do not use these types of numbers when explaining radiation therapy to patients is because it is not medically relevant. Physicians expect that patients treated with that amount of radiation due to the advanced state of their cancers will die long before the radiation causes more cancer. But Nancy did not understand she was about to die. Instead she believed, as she kept telling friends and family, that WBRT would make her brain "inhospitable to cancer." Indeed, she assumed that WBRT would add many productive years to her life. If Dr. R. had told Nancy the amount of radiation his proffered treatment would expose her to in the understandable way that Kevin discovered after her death, she would have wondered how she could survive such an exposure. What a physician considers medically irrelevant could be an eye-opener for the patient.

Yet Dr. R never hinted that the chance of Nancy surviving beyond a few months was slim. To the contrary, he spoke of "years" of survival without debilitating effects and explicitly stated that WBRT would ward off the brain tumors' detrimental effects. And neither Dr. R nor Dr. O1 told Nancy that eight prognostic tests place patients with brain metastases into statistically significant survival categories (Nieder, Bremnes, and Andratschke 2009). Highlighted in bold italic in table 1 is where Nancy placed in each prognostic test. Overall, she fell into the one-to-four-month median survival category. As the prognosticators indicated that she would, Nancy died less than three months after her first WBRT treatment.

After WBRT

The official record of Nancy's twenty-one radiation treatments (thirteen to her brain and eight to her neck) is a single page dated nine days after her treatment ended. The page is signed not by Dr. R but by another radiation oncologist who stepped in when Dr. R took a vacation during

TABLE 1
Comparison of Eight Prognostic Point Scores for Whole Brain Radiation Therapy

Name (# studied)	PS	Age	EM	CP	SR	Brain Metastases #	Brain Metastases Volume	Brain Metastases When Found	Class & Point Score (median survival in months) I	II	III	IV
RPA (1,200)	***KPS ≥ 70***	< 65	***Yes***/No	Yes/***No***					All favorable (4–9)	***Other (3)***	KPS < 70 (2)	
Rotterdam (1,292)	ECOG 0–1 vs 2–3		Limited vs extensive		Good to little response				ECOG 0–1, limited EM/CP, good SR	Other	***ECOG 2–3 & limited EM / CP or extensive EM / CP & little SR***	
SIR (65)	***KPS 80–100 = 2 pts;*** 60–70 = 1 pt	≤ 50 2 pts; 51–59 = 1 pt	No systemic disease or CR = 2 pts; PR or stable disease = 1 pt			1 = 2 pts, 2 = 1 pt	Largest < 5 mL = 2 pts; 5–13 mL = 1 pt ***(size unknown)***		8–10	4–7	***1–3; don't know size of Nancy's brain tumors, so score could be 4, then class II***	
									(6.3)	(3.3)	*(1.6)*	
BSBM (110)	***KPS 80–100 = 1 pt***		None = 1 pt	Yes = 1 pt					3	2	*1*	0
									(9)	(4)	*(3)*	(2)
GPA (5 trials)	KPS 90–100 1 pt; ***70–80 .5 pt***	< 50 1 pt; 50–59 .5 pt	None = 1 pt			1 = 1 pt			3.5–4 (9.5–21.7)	3 (4.3–17.5)	1.5–2.5 (2.5–5.9)	***0–1 (1.6–3.7)***

Continued

TABLE 1—*Continued*

Name (# studied)	PS	Age	EM	CP	SR	Brain Metastases #	Brain Metastases Volume	Brain Metastases When Found	Class & Point Score (median survival in months) I	II	III	IV
Rades (1,085)	***KPS ≥ 70 = 5 pts***, <70 = 1 pt	≤ 60 4 pts, ***>60 3 pts***	None = 5 pts, ***else 2 pts***					> 8 mos = 4, ***≤ 8 mos = 3***	17–18 (5.0)	14–16 (2.5)	***11–13; (1.6)***	9–10 (1.3)
Chao (157)	***KPS 70–80 = 1 pt***; ≤ 60 = 2 pts		***Bone = 1 pt; liver = 2 pts***					≤ 12 mos = 1 pt	0–1 (6.1)	2 (3.9)	3 (2.8)	***> 3 (1.9)***
Golden (169)		<65 = 1 pt	None = 1 pt			≤ 3 1 pt			3 (3.5)	2 (2.3)	1 (2.1)	***0 (1.6)***

Notes: Nancy's scores are in ***boldface***. Empty field means not used in scoring. RPA = recursive partitioning analysis, SIR = score index for radiosurgery, KPS = Karnofsky performance score, RTOG = Radiation Therapy Oncology Group, BSBM = basic score for brain metastases, GPA = graded prognostic assessment, ECOG = Eastern Cooperative Oncology Group, CR = complete remission, PR = partial remission, PS = performance status, EM = extracranial metastases, CP = controlled primary tumor, SR = steroid treatment response, pts = points, mos = months, mL = milliliter.

Source: Adapted from Carsten Nieder, Roy M. Bremnes, and Nicolaus H. Andratschke. 2009. Prognostic Scores in Patients with Brain Metastases from Non-Small-Cell Lung Cancer. *Journal of Thoracic Oncology* 4(11):1337–41. Used with permission.

Nancy's treatment. There is no documentation of the radiation dosage that Nancy actually received at each visit.

Nancy completed the thirteen WBRT treatments that Dr. R recommended but stopped the radiation treatments on her neck at eight because she was barely able to talk or swallow after the eighth treatment. In fact, the pain became so intense on April 9 that she and Herb went to the emergency room of their local hospital, where Nancy received a seven-day course of prednisone to ease the swelling in her throat. A few days after the visit to the emergency room, she and Herb met with Dr. R to explain why she curtailed the neck treatments. At the appointment, Dr. R told Nancy he disagreed with her decision, insisting that the full treatment regimen would have provided her with pain-free "years." Since Nancy still had serious throat pain, she dismissed his claim.

Nancy asked Dr. R about hospice as an alternative to the radiation that was now causing her so much discomfort. In individual phone calls to their children shortly after their appointment with Dr. R, Herb and Nancy reported that Dr. R responded angrily to Nancy's query about hospice. Hospice was "fine," he told them, "if you want to spend the rest of your life on opiates, doped into oblivion, lying in your own BMs." Herb, age eighty-three, told his children that he and Dr. R almost came to blows.

Everything that Dr. R insisted would be prevented by WBRT occurred within four weeks of the treatment's end. Nancy became incontinent. She could not shower or dress herself. She could walk only in a slow shuffle, leaning heavily on another person, measuring progress in inches. She was unable to make simple decisions. One afternoon, Kevin found her trying in vain to balance her checkbook; she had forgotten how to add and subtract.

When Nancy saw Dr. O1 on April 15, she could barely talk. He suggested they try more chemotherapy after her body recovered from the WBRT. In a hoarse whisper Nancy told him, "I can't envision having any more chemo."

Dr. O1 then said he planned on doing an MRI of her neck and brain in about three weeks "to assess the response to the radiation." Kevin sighed audibly and interrupted Dr. O1.

> I apologize for being blunt, but I've looked at various studies on metastases in the brain, and the studies indicate that only about 12 percent . . . of the people are even alive after four months. No one is alive after a year. And I'm just very concerned about our family

> situation. . . . I'm feeling like we need help at home. . . . I've been wanting to start a relationship with hospice. But Mom keeps hearing additional MRIs, additional scans. (digital recording, April 15, 2010)

Dr. O1 responded that he was "a big believer in hospice. And I think one of the decisions may be, either now or soon, to get them involved." But, he added, he wanted to go over all the options before discussing hospice. "For some people," he explained, "hearing the numbers . . . would be a reason not to do anything. For others, every week is important and they want to be as aggressive as they can. So we've got to go over all of the options and then work through what she wants or what's best for her."

Kevin pleaded, "We're also a family. And I'm watching my father having less and less ability to take care of things at home." Dr. O1 expressed sympathy but did not want to stop discussing treatment. "If our focus is treating the disease and prolonging life, then that's what we do. We don't bring hospice involved [*sic*]."

As Nancy, Herb, and Kevin left his office, Dr. O1 assured Nancy that he would continue seeing her at least once a month no matter what she decided about hospice (digital recording, April 15, 2010). Although Dr. O1 was trying to be evenhanded, throughout the conversation the arc of his proposed end-of-life care bent toward additional treatment. During the year he saw Nancy, he often spoke of being in favor of reviewing "all" options, yet he never mentioned hospice in any conversation until a family member broached the topic.

After leaving Dr. O1's office, Nancy, Herb, and Kevin headed for an appointment with Dr. P, Nancy's primary care physician. Before entering the hospice program, hospice requires two physicians to confirm that a patient is expected to live no more than six months. During their visit, Dr. P, and later that day Dr. O1, authorized Nancy's entrance into hospice.

The Efficacy of Palliative Care

No studies have compared patients with metastatic NSCLC who opted for standard oncology treatments with similar patients who opted for only palliative care. One small, nonrandomized study of 151 subjects with metastatic NSCLC, however, did compare patients who received early palliative care plus standard oncology treatment with patients who received only the standard treatment. Researchers found that early

palliative care led to significant improvement in patients' quality of life and mood. In addition, the palliative care group not only had less aggressive (i.e., debilitating) treatments at the end of life, but they also lived longer than the patients receiving only standard oncology treatments—11.6 months versus 8.9 months median survival (Temel et al. 2010). Other studies confirm that palliative care concurrent with standard oncologic care results in better outcomes for both patients and caregivers (Connor et al. 2007; Smith et al. 2012).

Disaster

Shortly after eating lunch one day in early May, Nancy fell in the kitchen. She was alone at the time and had no memory of what precipitated the fall. By the next day, a dark bruise covered half her face. She looked like the loser in a boxing match.

When Jackie visited shortly afterward, nothing could have prepared her for the change in her mother. She was placid, childlike, confused. She would fall asleep sitting at the kitchen table holding a spoonful of food in midair.

Herb hired two twenty-four-hour home health aides; one worked during the week and the other on the weekend. Nancy never acknowledged her deterioration or her sudden need for round-the-clock help. "She acts like taking twenty minutes to walk down a short hallway and needing two people to dress you (and it still takes ninety minutes) is perfectly normal, been doing it forever," Jackie wrote to a friend in an email.

Nancy's personality changed utterly. Before the WBRT, when Herb suggested that Jackie help her mother shower, Nancy declined, telling her daughter, "You've never seen me naked. I don't think we'd be comfortable with that." Now Nancy never commented on her need for help bathing, dressing, and toileting. Nor did she express any embarrassment in light of that need. "Like a piece of her brain is dead," was how one of her sons characterized the personality change.

Nancy's Final Days

In late May, just before the entire family and many friends converged on Herb and Nancy's home for a belated celebration of Nancy's eightieth birthday, Jackie arrived at her parents' home to find her mother flailing

and shrieking at Herb and the home health aide. Nancy recognized Jackie immediately and beckoned to her as if to a savior. Nancy told her daughter gratefully, "If you hadn't come, I'd be dead." Nancy was convinced that her husband and the home health aide were trying to burn her. Nancy begged Jackie never to leave, insisting that if she left, "they will become evil again."

By the time her children left town a few days later, Nancy had only intermittent slivers of strange lucidity. While talking to Glenn on the phone after he returned to his faraway home, she said, "I love you. But love is superficial. I don't know what it means." The next day, when Herb received a noontime phone call from a telemarketer, he succumbed to stress and exploded at the intrusion. As he lambasted the hapless telemarketer, Nancy looked up from the chair she had been sitting in. After not uttering a coherent sentence all morning she said quietly and calmly, "Tell them your wife has a terminal illness and has only a limited amount of time to live." But when the hospice nurse arrived an hour later, Nancy was back in her fog. She could only mutter, "It's crucial. It's crucial," over and over again.

Although a hospice nurse now visited daily and Herb ordered a Hoyer lift to get Nancy in and out of bed, by early June she had become so disoriented that Herb found home care too difficult to handle. She entered the hospice wing of a nearby hospital on June 4. For almost her entire stay in the hospital she was either incoherent or noncommunicative.

During her stay in hospice, to his credit Dr. O1 visited Nancy on June 8 and June 11. During one of those visits, Jackie asked to talk to him. They stepped out into the hallway, and Jackie complained to him that Dr. R had frightened her mother by conjuring the consequences of forgoing brain radiation. Yet WBRT and the neck radiation had been enormously detrimental to Nancy's quality of life. And despite the potential ill effects of radiating a brain, Dr. R had never made any attempt to contact Nancy after administering his treatments. He had not seen or, as far as Nancy's family knew, even learned the results of his radiation "therapy." How, Jackie wondered, can a physician radiate a patient's brain and subsequently not gauge the results?

Dr. O1 listened to Jackie's concerns. He was not defensive. He agreed that, yes, WBRT had not been a good decision in Nancy's case, but he had seen it work for other patients, including one patient who was still alive after two years. You just never know, he maintained.

Then Dr. O1 told Jackie that when he saw the tumor on Nancy's liver in mid-June 2009, he knew that her illness was terminal. "Why didn't you tell her?" Jackie asked. He echoed the rationale of the physicians that Jackie had read about almost a year earlier in the *New York Times*. He told her he thought that most patients did not want to know they had a terminal illness or if knowing was best for them.

Not long after that conversation, on June 15, 2010, two days before her sixty-first wedding anniversary, Nancy Bild Wolf died.

Changing the Approach to End-of-Life Care

At many junctures, Nancy's physicians could have changed the trajectory of this account. At the outset, Nancy should not have had the chest X-ray in March 2009 revealing her lung cancer. The U.S. Preventive Services Task Force (USPSTF) specifically advises against screening the elderly (people seventy-five and older) for colorectal, breast, prostate, and cervical cancers. Lung cancer did not appear on that list in 2009 because there was no evidence that screening for asymptomatic lung cancer at any age decreased mortality. Although the guidelines have changed slightly since Nancy's death, the USPSTF continues to note that there is scant evidence that screening for lung cancer decreases mortality. The USPSTF advises against certain screenings because the organization has long maintained that the treatments offered after a positive screening can have more negative than positive effects (U.S. Preventive Services Task Force 2013). This certainly was true in Nancy's case. After her death, family members agreed that she would have been better off if the cancer had not been discovered until she was symptomatic, three months before her death. Between March 2009, when the cancer was first discovered via the chest X-ray, and March 2010, only the cancer treatments—not her illness—caused her debilitating symptoms.

After discovering the cancer, Nancy's primary care physician should have remained closely involved in her care. During the fifteen months of Nancy's illness, he was the only physician who told her that she was dying, and he conveyed the news with ease and compassion. "I'm so sorry," he told her immediately after informing her of the results of the chest X-ray. "You've had a wonderful life." He did not have to be blunt. He did not have to tell Nancy that the illness he had just discovered

would quickly kill her. Nevertheless, Nancy understood what he was saying. She did not quite believe him at that point, however, and every physician she saw subsequently nullified his message. If Dr. P had been an integral part of Nancy's cancer care team, he could have helped her better understand her illness (Klabunde et al. 2009). Effectively replacing Dr. P with Dr. O1 was largely Nancy's decision, albeit not necessarily a conscious one. She sought a cure. Dr. P had none to offer. She thought Dr. O1 did.

Unlike Dr. P's uncomplicated message that Nancy's life would soon end, Drs. S, O1, O2, O3, and R consistently overestimated Nancy's life expectancy and exaggerated the efficacy of the treatments they proposed. This is not unusual. One study indicates that physicians who treat terminally ill patients inflate their survival time by a factor of 5.3 (Christakis and Lamont 2000). While physicians argue that optimism about life expectancy provides dying patients with hope, routine optimism also benefits physicians by allowing them to avoid uncomfortable conversations with patients who are facing a terminal illness (Kiely, Stockler, and Tattersall 2011; Teutsch 2003; Weeks et al. 2012). This unrealistic optimism can have negative consequences for the very patients physicians are trying to help, prompting patients to delay any consideration of hospice—an institution that not only ensures that patients remain comfortable for longer but also, studies are beginning to show, can prolong life if chosen early enough in the course of a terminal illness (Temel et al. 2010).

There are creative ways in which Dr. O1 could have been as clear as Dr. P when discussing prognosis with Nancy. Adjuvant! Online—an instrument to help physicians discuss with early-stage cancer patients the risks and benefits of therapy—would have been useful in this regard. If Dr. O1 had used this tool during one of Nancy's first office visits, he could have demonstrated to her that a seventy-nine-year-old woman with lung cancer recently staged at IIB after a surgical resection had slim odds of surviving five years and that chemotherapy would not improve those odds by much. According to Adjuvant! Online (n.d.), only 32 percent of patients like Nancy who choose chemotherapy are still alive after five years, versus 25 percent who reject chemotherapy—statistics different from the more optimistic numbers originally supplied by Drs. O1 and O2. Just as Dr. P's expression of regret at his finding on her chest X-ray gave Nancy a fleeting understanding of her illness, the use of Adjuvant! Online by Dr. O1 likewise could have helped

Nancy understand what to expect. This tool might also have preempted Dr. O1's use of anecdotal evidence for the efficacy of the treatments he proposed, never a helpful strategy except to make everyone present feel momentarily better about a sad situation. If Dr. O1 had sat with Nancy in front of a computer and used this tool at one of their early appointments, her treatment decisions might have been different. Nancy, after all, decided to undergo chemotherapy only *after* her cancer had metastasized to her liver; Adjuvant! Online does not even provide survival rates for stage IV cancer patients because those patients have so little time left. That fact alone would have vividly illustrated for Nancy a realistic prognosis.

Nancy's understanding of her illness would have benefited from other simple strategies, notably the ask-tell-ask method of relaying information to patients with serious illnesses. Rather than ask her if she wanted to know her prognosis, Dr. O1 assumed at every step that she did not want to know that her illness was terminal. This default assumption encourages patients to make choices they might not have made if they had had a better understanding of their illness. Rather than presume, Nancy's physicians should have asked at each visit what her concerns were that day, what she understood about the course of her illness thus far, and how much more she wanted to know about it. Specifically, did she want to know her prognosis? After responding to that day's questions, Nancy's physicians should have asked her to repeat what she just heard. Bad news, under the best of circumstances, is not only difficult to deliver; it is hard to listen to and absorb. Doctors should always confirm that patients have heard them correctly by asking them to repeat in their own words the information they have just received (Boxer and Snyder 2009). Ironically, in Nancy's case, she did hear her physicians. Their ambiguous messages were laced with implied optimism. The ask-tell-ask exercise might also have helped her physicians hear themselves.

Most cancer patients state that they want their physicians to be honest, forthright, and complete when explaining prognosis and treatment (Hagerty et al. 2005). Yet oncologists are notably uncomfortable breaking bad news to patients, for several reasons. Without substantive formal training in how to relay bad news, they are unsure of how to respond to patients' negative emotions during difficult discussions (Baile et al. 1999; Keating et al. 2010). In particular, doctors fear eliminating patients' hope if they do not consistently offer treatment throughout the course of a terminal illness. There is no evidence, however, that being

honest and direct causes depression or eliminates hope. To the contrary, there is evidence that failing to provide appropriate information can contribute to patients' unnecessary pain and suffering, sow confusion, and lead to a diminished quality of life (Kiely, Stockler, and Tattersall 2011; Quill 2011; Smith and Longo 2012; Tulsky 2005).

When a physician tells someone who is dying, "I can't cure you," then follows that declaration with a lengthy description of potential treatments, the doctor has immediately nullified the "I can't cure you" message. What the patient hears instead is: your illness might not be curable but it is treatable. Elderly patients in particular have learned through myriad experiences that physicians can treat many illnesses that they cannot cure. These illnesses range from the minor and self-limiting (e.g., a cold) to the serious and chronic (ulcerative colitis, one of many diseases that is treatable but not curable). Equally confusing, when physicians use phrases such as "survival benefit," "survival rates," "overall survival," and "pain-free years," patients think they have heard their doctors say they can "survive" their illness and look forward to many more "years" of life if they choose to undergo the recommended treatments. Doctors who provide anecdotal evidence in support of treatment bolster that interpretation. If patients are to understand the nature of a serious illness, their options in the face of that illness, and the ramifications of each option, then obfuscation has no place in such conversations (Hagerty et al. 2005).

This tendency to offer treatments to the terminally ill in lieu of an honest, clear prognosis is not only a propensity of individual physicians. It is a systemic problem. Most American physicians are embedded in a fee-for-service system that pays separately for each office visit and each service performed. But other models of health care payment are far better at keeping costs down than fee-for-service. To take only two examples: one method pays a single sum for all services delivered during an illness, and another pays a fixed sum for each patient's care during a month or a year. In fact, of all payment models, fee-for-service is the only one based on dividing health care episodes into individual components (Bodenheimer and Grumbach 2009). This creates a built-in incentive for physicians to order a greater number of services, some of which may be unusually expensive, others redundant or wholly unnecessary, and still others, as in Nancy's case, futile. Hospice utilization in particular is affected negatively by fee-for-service. One study shows that patients seeking care under such a system are less likely to enroll in hospice

TABLE 2
Nancy Wolf's Medical Bills

Medical Service	Billed	Paid
Lung surgery & hospitalization	$78,832	$25,109
Chemotherapy	$98,286	$50,725
Radiation treatment	$78,015	$10,491
X-ray, CT, PET, MRI scans	$120,710	$24,280
Home health aides	$7,989	$7,879
Hospice	$27,445	$16,201
Prescription drugs	$32,872	$25,034
Miscellaneous medical services	$21,992	$17,716
Total	**$466,141**	**$177,435**

programs and are referred to hospice later in their illness than are patients under other payment systems (McCarthy et al. 2003). When treating the terminally ill, oncologists might unconsciously ignore hospice as an option equivalent to cancer treatments because hospice is not one of the many services that oncologists provide and subsequently receive payment for. American physicians also are products of a larger culture that equates medical treatment, no matter how pointless, with hope and is uncomfortable with death and the medical institution most closely associated with death—hospice.

Despite their good intentions, her physicians' constant offers of treatments and diagnostics did Nancy no favors. In the name of treating her untreatable illness, doctors exposed her to a host of treatments with debilitating side effects: lung surgery, four infusions of carboplatin/Alimta, four months of the oral drug Tarceva, thirteen WBRT treatments, and eight neck/spine-directed radiation treatments. To monitor the fifteen-month illness that Dr. O1 recognized as terminal by month 4, medical personnel also radiated Nancy many times in many forms: fifteen CT scans, three PET scans, and twelve X-rays. She also had seven radiation-free MRIs.

The monetary cost of Nancy's medical care—to her as an individual and to society—was equally impressive. As table 2 shows, Medicare, private insurance, or Herb approved payments of $177,435 (38% of the $466,141 in billed charges). Medicare paid 76 percent, private insurance paid 10 percent, and Nancy and Herb paid 14 percent. The charges were reduced, as is the common practice, to adhere to Medicare rules and insurance contracts with health care providers.

The high costs at the end of Nancy's life were not unusual—one-fourth of all Medicare costs are for care in the last year of life (Hogan et al. 2001). Nancy's saga hints at how physicians can better help patients make medical decisions that are less damaging to them and less costly to the health care system.

When Dr. O1 told Jackie that WBRT had not been a good decision in Nancy's case but that "you just never know" about a treatment's efficacy in advanced cases of NSCLC, he admitted a moment later that he did know. No matter the treatment, Nancy did not have long to live. Dr. O1 knew this by early June 2009. Yet the automatic offer of treatment continued almost until her death in mid-June 2010—a logical extension of a health care system that routinely overdiagnoses and overtreats even healthy, asymptomatic patients. This overuse of medical resources offers no benefit to patients, can put them at risk for harm, and wastes as much as 30 percent of health care dollars. Yet it is a largely understudied problem (Cassel and Guest 2012; Korenstein et al. 2012).

When terminally ill patients receive honest and thorough assessments from their physicians and thus are more apt to reject futile treatment and choose palliative care earlier rather than later, they enjoy a better quality of life than patients who do not (Connor et al. 2007; Smith et al. 2012; Temel et al. 2010). They also have significantly lower health care costs (Zhang et al. 2009). These lower costs benefit families long after the patient is gone; medical expenses are a factor in more than 60 percent of personal bankruptcies in the United States (Himmelstein, Thorne, and Woolhandler 2011; Himmelstein et al. 2009; Lovenheim 2009).

Physicians are wrong when they tell terminally ill patients that "doing something" (in other words, pursuing treatment) "is better than doing nothing" ("nothing" usually meaning choosing hospice care instead of treatment). Although this claim is a common one, and more than one of Nancy's physicians made the claim, it demands universal rethinking.

Families Collude with Doctors

Physicians who treat the terminally ill are not the only ones who hide truths from those patients as a matter of course. Family members do too. While the vast majority of terminally ill patients say their families help them feel hopeful (Hagerty et al. 2005), when physicians hide basic truths from patients, family members tend to follow doctors' leads and

studiously avoid the conversations that patients might find especially inspiring at the end of their lives. Nancy's family faced precisely that situation. Despite their unique forms of medical knowledge and ability to be proactive in many realms (even writing and jointly signing a letter to Dr. O1 immediately after Nancy's WBRT treatments, complaining that she had not been fully informed of side effects before agreeing to the treatment), they could not disentangle themselves from their family history to contradict what she heard her doctors telling her. In far less trying circumstances than her illness, Nancy could be defensive and accusatory, especially with people she loved, and so family members had always found it difficult to speak with her about important truths. Her children learned, for example, that they could not discuss painful childhood memories with her without almost equally painful recriminations in adulthood.

So despite their disquiet, Nancy's children and her husband, Herb, followed doctors' leads and never discussed a realistic prognosis with her. American families in general tend to do this for a variety of reasons usually having to do with their own unique family dynamics and feelings about death and medical treatment. Nancy's husband and three oldest children worried that in trying to tell her that she had a terminal illness, she would lash out and accuse them of wanting her dead. They feared even more that if they discussed with her the futility of treatment and she heeded their advice, on her deathbed she would indict them all for killing her.

Unlike patients' family members, doctors are in a better position to speak frankly with the terminally ill. Concomitantly, when physicians are not compassionately forthright with patients, physicians make difficult family situations worse. If Nancy's doctors had been more realistic with her about her prognosis, family members would have helped her face the end of her life with love and memories in lieu of the debilitating, futile treatments she chose. Instead, her doctors' words and actions bolstered family pathologies rather than encouraged family members to discard them during this crisis.

In not taking Nancy Wolf's individuality into account, her doctors' mechanical optimism did her a disservice. She was a feisty woman. As a college student in the 1940s, she fought racial discrimination. As a parent in the 1960s, she spoke out against the Vietnam War. She demonstrated courage throughout her life, combating the status quo. In keeping with that proclivity, Nancy also believed that change was

needed in the approach to end-of-life treatment. She shook her head in disbelief when some commentators and politicians characterized as "death panels" the provision in the Affordable Care Act that provided payment to physicians for discussing with patients their preference for end-of-life care. Accordingly, well before her illness, Nancy made sure that she had advance directives. She appointed a health proxy. Yet rather than be straightforward with her, a patient who had long ago considered the implications of end-of-life care, neither Dr. O1 nor Dr. R ever informed Nancy that her illness was terminal. By the time that became evident to her and she turned to hospice, the effectiveness of the array of palliative and supportive services offered by hospice was greatly diminished (Huskamp et al. 2009).

Physicians rationalize that the treatments they offer to dying patients instill hope and in offering that type of hope they have done their best. Yet at the end of a life, couching hope primarily in terms of medical treatment rarely enhances individual or societal well-being. To the contrary, costly and futile treatments and diagnostics often do tangible harm to patients, their families, and the health care system. While elusive cures can offer one form of hope, the end of suffering suggests another. Opportunities for families to acknowledge that death is part of life's continuum likewise inspire hope, as do occasions for families to discuss the value and meaning of the life that is about to end. Patients who understand that the end of their life is near can also complete unfinished business and spend time doing the things they enjoy most. Indeed, hope can take endless forms, constrained only by culture and personal and familial inclinations. In limiting a patient's hope to one narrow avenue—treatment that is unlikely to be successful but is likely to be costly in physical, emotional, monetary, and societal terms—American physicians unintentionally ensure that patients and their families will miss countless opportunities for inspiring hope in both the terminally ill and the family members affected by their loved one's illness and death.

References

Adjuvant! Online. n.d. Adjuvant! Online: Decision Making Tools for Health Care Professionals. Available at www.adjuvantonline.com (accessed July 18, 2013).

Altekruse, S.F., C.L. Kosary, M. Krapcho, et al., eds. 2010. Cancer of the Lung & Bronchus (Including Non-Small-Cell and Small-Cell Lung Cancer Combined). *SEER Cancer Statistics Review, 1975–2007*. Available at http://seer.cancer.gov/csr/1975_2007/browse_csr.php?section=15&page=sect_15_table.10.html and http://seer.cancer.gov/csr/1975_2007/browse_csr.php?section=15&page=sect_15_table.14.html (accessed May 28, 2013).

Antoniou, D., K. Kyprianou, G.P. Stathopoulos, et al. 2005. Response of Radiotherapy in Brain Metastases and Survival of Patients with Non-small Cell Lung Cancer. *Oncology Reports* 14:733–36.

Arriagada, R., B. Bergman, A. Dunant, T. Le Chevalier, J.-P. Pignon, and J. Vansteenkiste. 2004. Cisplatin-Based Adjuvant Chemotherapy in Patients with Completely Resected Non-Small-Cell Lung Cancer. *New England Journal of Medicine* 350:351–60.

Baile, W.F., G.A. Glober, R. Lenzi, E.A. Beale, and A.P. Kudelka. 1999. Discussing Disease Progression and End-of-Life Decisions. *Oncology* 13:1021–31.

Barton, R. 2008. Inoperable Brain Metastases from Non-small Cell Lung Cancer: What Part Does Whole Brain Radiotherapy Play in Standard Treatment? *Thorax Journal* 63:1–2.

Bodenheimer, T.S., and K. Grumbach. 2009. *Understanding Health Policy: A Clinical Approach*. New York: McGraw-Hill.

Bonomi, P., K.M. Kim, D. Fairclough, et al. 2000. Comparison of Survival and Quality of Life in Advanced Non-Small-Cell Lung Cancer Patients Treated with Two Dose Levels of Paclitaxel Combined with Cisplatin versus Etoposide with Cisplatin: Results of an Eastern Cooperative Oncology Group Trial. *Journal of Clinical Oncology* 18:623–31.

Boxer, H., and S. Snyder. 2009. Five Communication Strategies to Promote Self-Management of Chronic Illness. *Family Practice Management* 6(5):12–16.

Cassel, C.K., and J.A. Guest. 2012. Choosing Wisely: Helping Physicians and Patients Make Smart Decisions about Their Care. *JAMA* 307(17):1801–2.

CDC (Centers for Disease Control and Prevention), National Center for Health Statistics. 2010. *United States Life Tables, 2006 and National Vital Statistics Reports*. June 28 (all males from table 2, all females from table 3, white females from table 6).

Christakis, N.A., and E.B. Lamont. 2000. Extent and Determinants of Error in Doctors' Prognoses in Terminally Ill Patients: Prospective Cohort Study. *BMJ* 320:469–72.

Comis, R.L. 2005. The Current Situation: Erlotinib (Tarceva®) and Gefitinib (Iressa®) in Non-small Cell Lung Cancer. *Oncologist* 10:467–70.

Connor, S.R., B. Pyenson, K. Fitch, C. Spence, and K. Iwasaki. 2007. Comparing Hospice and Nonhospice Patient Survival among Patients Who Die within a Three-Year Window. *Journal of Pain Symptom Management* 33:238–46.

DeAngelis, L.M., J.-Y. Delattre, and J.B. Posner. 1989. Radiation-Induced Dementia in Patients Cured of Brain Metastases. *Neurology* 39:789–96.

Douillard, J.-Y., R. Rosell, M. De Lena, et al. 2006. Adjuvant Vinorelbine plus Cisplatin versus Observation in Patients with Completely Resected Stage IB—IIIA Non-Small-Cell Lung Cancer (Adjuvant Navelbine International Trialist Association [ANITA]): A Randomized Controlled Trial. *Lancet* 7:719–27.

Fruh, M., E. Rolland, J.-P. Pignon, et al. 2008. Pooled Analysis of the Effect of Age on Adjuvant Cisplatin-Based Chemotherapy for Completely Resected Non-Small-Cell Lung Cancer. *Journal of Clinical Oncology* 26:3573–81.

Gatzemeier, U., A. Pluzanska, A. Szczesna, et al. 2007. Phase III Study of Erlotinib in Combination with Cisplatin and Gemcitabine in Advanced Non-Small-Cell Lung Cancer: The Tarceva Lung Cancer Investigation Trial. *Journal of Clinical Oncology* 25:1545–52.

Genentech. 2013. Tarceva Fact Sheet. Available at http://www.gene.com/download/pdf/tarceva_prescribing.pdf (accessed May 28, 2013).

Gervais, R., G. Robinet, C. Clément-Duchêne, et al. 2013. Pemetrexed and Carboplatin, and Active Option in First-Line Treatment of Elderly Patients with Advanced Non-small Cell Lung Cancer (NSCLC): A Phase II Trial. *Lung Cancer* 80:185–90.

Goldberg, S.W., J.L. Mulshine, D. Hagstrom, and B.S. Pyenson. 2010. An Actuarial Approach to Comparing Early Stage and Late Stage Lung Cancer Mortality and Survival. *Population Health Management* 13:33–46.

Grønberg, B.H., R.M. Bremnes, Ø. Fløtten, et al. 2009. Phase III Study by the Norwegian Lung Cancer Study Group: Pemetrexed plus Carboplatin Compared with Gemcitabine plus Carboplatin as First-Line Chemotherapy in Advanced Non-Small-Cell Lung Cancer. *Journal of Clinical Oncology* 27:3217–24.

Hagerty, R.G., P.N. Butow, P.M. Ellis, et al. 2005. Communicating with Realism and Hope: Incurable Cancer Patients' Views on the Disclosure of Prognosis. *Journal of Clinical Oncology* 23:1278–88.

Hall, W.A., H.R. Djalilian, E.S. Nussbaum, and K.H. Cho. 2000. Long-Term Survival with Metastatic Cancer to the Brain. *Medical Oncology* 17:279–86.

Hartocollis, A. 2009. At the End, Offering Not a Cure but Comfort. *New York Times*, August 19.

Hensing, T.A., A.H. Peterman, M.J. Schell, J.-H. Lee, and M.A. Socinski. 2003. The Impact of Age on Toxicity, Response Rate, Quality of Life, and Survival in Patients with Advanced, Stage IIIB or IV Nonsmall Cell Lung Carcinoma Treated with Carboplatin and Paclitaxel. *Cancer Journal* 98:779–88.

Herbst, R.S., D. Prager, R. Hermann, et al. 2005. TRIBUTE: A Phase III Trial of Erlotinib Hydrochloride (OSI-774) Combined with Carboplatin and Paclitaxel Chemotherapy in Advanced Non-Small-Cell Lung Cancer. *Journal of Clinical Oncology* 23:5892–99.

Himmelstein, D.U., D. Thorne, E. Warren, and S. Woolhandler. 2009. Medical Bankruptcy in the United States, 2007: Results of a National Study. *American Journal of Medicine* 122:741–46.

Himmelstein, D.U., D. Thorne, and S. Woolhandler. 2011. Medical Bankruptcy in Massachusetts: Has Health Reform Made a Difference? *American Journal of Medicine* 124:224–28.

Hogan, C., J. Lunney, J. Gabel, and J. Lynn. 2001. Medicare Beneficiaries' Costs of Care in the Last Year of Life. *Health Affairs* 20:188–95.

Huskamp, H.A., N.L. Keating, J.L. Malin, et al. 2009. Discussions with Physicians about Hospice among Patients with Metastatic Lung Cancer. *Archives of Internal Medicine* 169(10):954–62.

Keating, N.L., M.B. Landrum, S.O. Rogers, et al. 2010. Physician Factors Associated with Discussions about End-of-Life Care. *Cancer* 116:998–1006.

Kiely, B.E., M.R. Stockler, and M.H.N. Tattersall. 2011. Thinking and Talking about Life Expectancy in Incurable Cancer. *Seminars in Oncology* 38(3):380–85.

Klabunde, C.N., A. Ambs, N.L. Keating, et al. 2009. The Role of Primary Care Physicians in Cancer Care. *Journal of General Internal Medicine* 24(9):1029–36.

Korenstein, D., R. Falk, E.A. Howell, T. Bishop, and S. Keyhani. 2012. Overuse of Health Care Services in the United States: An Understudied Problem. *Archives of Internal Medicine* 172(2):171–78.

Kubota, K., K. Watanabe, H. Kunitoh, et al. 2011. Phase III Randomized Trial of Docetaxel plus Cisplatin versus Vindesine plus Cisplatin in Patients with Stage IV Non-Small-Cell Lung Cancer: The Japanese Taxotere Lung Cancer Group. *Journal of Clinical Oncology* 22:254–61.

Leopold, E. 1999. *A Darker Ribbon: Breast Cancer, Women, and Their Doctors in the Twentieth Century*. Boston: Beacon Press.

Li, B., J. Yu, M. Suntharalingam, et al. 2000. Comparison of Three Treatment Options for Single Brain Metastasis from Lung Cancer. *International Journal of Cancer* 90:37–45.

Lovenheim, S. 2009. New Study: Bankruptcy Tied to Medical Bills. *Washington Post*, June 4.

Mack, J.W., and T.J. Smith. 2012. Reasons Why Physicians Do Not Have Discussions about Poor Prognosis, Why It Matters, and What Can Be Improved. *Journal of Clinical Oncology* 30(22):2715–17.

McCarthy, E., R. Burns, R. Davis, and R. Phillips. 2003. Barriers to Hospice Care among Older Patients Dying with Lung and Colorectal Cancer. *Journal of Clinical Oncology* 21:728–35.

MedPAC and Centers for Medicare & Medicaid Services. 2009. Hospice Services Payment System and Wage Index. Available at www.medpac.gov/documents/MedPAC_Payment_Basics_09_hospice.pdf and www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/Hospice/Downloads/FY2010_Hospice_WI.zip (accessed July 20, 2012).

Merton, V. 1993. The Exclusion of Pregnant, Pregnable, and Once-Pregnable People (a.k.a. Women) from Biomedical Research. *American Journal of Law and Medicine* 19:369–451.

Nieder, C., R.M. Bremnes, and N.H. Andratschke. 2009. Prognostic Scores in Patients with Brain Metastases from Non-small Cell Lung Cancer. *Journal of Thoracic Oncology* 4:1337–41.

Pignon, J.-P., H. Tribodet, G.V. Scagliotti, et al. 2008. Lung Adjuvant Cisplatin Evaluation: A Pooled Analysis by the LACE Collaborative Group. *Journal of Clinical Oncology* 26:3552–59.

Quill, T.E. 2011. Initiating End-of-Life Discussions with Seriously Ill Patients: Addressing the "Elephant in the Room." In *Care at the Close of Life: Evidence and Experience*, eds. S.J. McPhee, M.A. Winkler, M.W. Rabow, et al., 3–11. New York: McGraw-Hill Medical.

Reck, M., N. van Zandwijk, C. Gridelli, et al. 2010. Erlotinib in Advanced Non-small Cell Lung Cancer: Efficacy and Safety Findings of the Global Phase IV Tarceva Lung Cancer Survival Treatment Study. *Journal of Thoracic Oncology* 5:1616–22.

Sandler, A.B., J. Nemunaitis, C. Denham, et al. 2000. Phase III Trial of Gemcitabine plus Cisplatin versus Cisplatin Alone in Patients with Locally Advanced or Metastatic Non-Small-Cell Lung Cancer. *Journal of Clinical Oncology* 18:122–30.

Scagliotti, G.V., R. Fossati, V. Torri, et al. 2003. Randomized Study of Adjuvant Chemotherapy for Completely Resected Stage I, II, or IIIA Non-Small-Cell Lung Cancer. *Journal of the National Cancer Institute* 95:1453–61.

Shepherd, F.A., J.R. Pereira, T. Ciuleanu, et al. 2005. Erlotinib in Previously Treated Non-Small-Cell Lung Cancer. *New England Journal of Medicine* 353:123–32.

Smith, T.J., L.A. Dow, E.A. Virago, J. Khatcheressian, R. Maysuyama, and L.J. Lyckholm. 2011. A Pilot Trial of Decision Aids to Give Truthful Prognostic and Treatment Information to Chemotherapy

Patients with Advanced Cancer. *Journal of Supportive Oncology* 9(2):79–86.

Smith, T.J., and D.L. Longo. 2012. Talking with Patients about Dying. *New England Journal of Medicine* 367(17):1651–52.

Smith T.J., S. Temin, E.R. Alesi, et al. 2012. American Society of Clinical Oncology Provisional Clinical Opinion: The Integration of Palliative Care into Standard Oncology Care. *Journal of Clinical Oncology* 30:880–87.

Smith-Bindman, R., J. Lipson, R. Marcus, et al. 2009. Radiation Dose Associated with Common Computed Tomography Examinations and the Associated Lifetime Attributable Risk of Cancer. *Archives of Internal Medicine* 169:2078–86.

Soon, Y.Y., M.R. Stockler, L.M. Askie, and M.J. Boyer. 2009. Duration of Chemotherapy for Advanced Non-Small-Cell Lung Cancer: A Systematic Review and Meta-Analysis of Randomized Trials. *Journal of Clinical Oncology* 27:3277–83.

Temel, J.S., J.A. Greer, A. Muzikansky, et al. 2010. Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. *New England Journal of Medicine* 363:733–42.

Teutsch, C. 2003. Patient-Doctor Communication. *Medical Clinics of North America* 87:1115–45.

Tulsky, J.A. 2005. Beyond Advance Directives: Importance of Communication Skills at the End of Life. *JAMA* 294(3):359–65.

U.S. Nuclear Regulatory Commission. 2011. Fact Sheet on Biological Effects of Radiation. Available at http://www.nrc.gov/reading-rm/doc-collections/fact-sheets/bio-effects-radiation.html (accessed May 28, 2013).

U.S. Preventive Services Task Force. 2013. Lung Cancer Screening Recommendation Statement. Available at http://www.uspreventiveservicestaskforce.org/3rduspstf/lungcancer/lungcanrs.htm (accessed August 22, 2013).

Waller, D., R.J. Stephens, N.H. Gower, et al. 2004. Chemotherapy for Patients with Non-small Cell Lung Cancer: The Surgical Setting of the Big Lung Trial. *European Journal of Cardio-thoracic Surgery* 26:17–82.

Weeks, J.C., P.J. Catalano, A. Cronin, et al. 2012. Patients' Expectations about Effects of Chemotherapy for Advanced Cancer. *New England Journal of Medicine* 367(17):1616–25.

Wheatley-Price, P., K. Ding, L. Seymour, G.M. Clark, and F.A. Shepherd. 2008. Erlotinib for Advanced Non-Small-Cell Lung Cancer in the Elderly: An Analysis of the National Cancer Institute of Canada Clinical Trials Group Study BR.21. *Journal of Clinical Oncology* 26:2350–57.

Zabel, A., S. Milker-Zabel, C. Thilmann, et al. 2002. Treatment of Brain Metastases in Patients with Non-small Cell Lung Cancer (NSCLC) by Stereotactic Linac-Based Radiosurgery: Prognostic Factors. *Lung Cancer Journal* 37:87–94.

Zhang, B., A.A. Wright, H.A. Huskamp, et al. 2009. Health Care Costs in the Last Week of Life: Associations with End-of-Life Conversations. *Archives of Internal Medicine* 169:480–88.

Zukin, M., C. Barrios, J. Pereira, et al. 2013. Randomized Phase III Trial of Single-Agent Pemetrexed versus Carboplatin and Pemetrexed in Patients with Advanced Non-Small-Cell Lung Cancer and Eastern Cooperative Oncology Group Performance Status 2. *Journal of Clinical Oncology* 31:1–5.

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