Commentary: "The Lake Wobegon Effect, a Natural Human Tendency to Overestimate One's Capabilities" (Wikipedia)

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> Welcome to Lake Wobegon, where all the women are strong, all the men are good-looking, and all the children are above average.
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> —Garrison Keillor

Having read the article by Wolf and Wolf in this issue of *The Milbank Quarterly*, the oncologist part of me asks, "Where's the beef?" This is typical care: Mrs. Wolf, an eighty-year-old former smoker but healthy woman, is found (serendipitously) to have a resectable lung cancer and is treated with a curative resection based on her physiological age rather than her chronological age, as suggested by most guidelines (Hurria 2013). Indeed, based on the evidence available when she was diagnosed (Henschke et al. 2006), screening is now recommended by the U.S. Preventive Health Services Task Force (Humphrey et al. 2013). Appropriately, Mrs. Wolf declined adjuvant chemotherapy, based on a somewhat informed choice. Then when her cancer recurred, she had a good response to chemotherapy, which lasted for at least four months. We have known for twenty years that compared with the best supportive care, chemotherapy gains the average person a few months of life and increases, from about 20 percent to about 50 percent, the chance of being alive one year later (ASCO 1997). The chemotherapy that Mrs. Wolf received, carboplatin and pemetrexed (Alimta®), is as successful as any other (Incollingo 2013; Patel, Socinski, and Garon 2012), and she likely did not have any nausea or lose her hair. Her recurrence was treated with FDA-approved erlotinib (Tarceva®) for second-line use in her type of lung cancer (NCI 2013). She got brain radiation and neck spine radiation, with fairly typical side effects. In

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addition, she was in the lucky 54 percent of cancer patients who actually used hospice and was with hospice for two months, many times the national average of eight days (Morden et al. 2012). She had a terrible last month with agitation, delirium, and increasing debility, which sounds like a nightmare, but cancer is a tough business, as is being eighty and having one's brain filled with "mets" (i.e., metastases) and being radiated.

In contrast, the palliative care specialist and primary care physician and communication-savvy oncologist in me is dismayed. We can do *so* much better with palliative care in the office (Cheng et al. 2013), even though most oncologists think they already offer palliative care (Abrahm 2012). Accordingly, oncologists' performance (when measured) must be improved (Blaney et al. 2012). The benefits of adjuvant therapy for non-small-cell lung cancer were overestimated twofold, and neither of Mrs. Wolf's oncologists used a widely available tool (AdjuvantOnline!) to explain realistic estimates. Furthermore, neither she nor her family ever fully understood the benefits of chemotherapy, and neither oncologist used easily available Decision Aids (ASCO 2011; Siminoff et al. 2006), which would have helped them weigh the risks and benefits.

The resulting miscommunication and misunderstanding, unfortunately, also are typical. No doctor ever used the "ask, tell, ask" method (Back and Tulsky 2009; Robinson et al. 2008). That is, *ask*, "What is your understanding of your disease? How much do you want to know about your situation?" Then, *tell*, in understandable terms and using numbers to enhance understanding. For example, "The average person will live about four months longer if she has chemotherapy. This can help, but does not cure, the disease. And the four main side effects are . . . " Finally, *ask*, "Now that we have had this discussion, what is your understanding of your situation?" It helps to mention at least some negative aspects in order to enhance understanding (Robinson et al. 2008), such as chemotherapy does not help at least half the people who get it and is never a cure. But because of this miscommunication and misunderstanding, most of the time Mrs. Wolf—like three-fourths of Americans with incurable lung cancer—believed she could be cured (Weeks et al. 2012).

We have known for fifteen years that patients who overestimate or deny their prognosis do not live any longer and are more likely to die "bad" deaths in the hospital, with resuscitation or on a ventilator (Smith

1998; Weeks et al. 1998). Following 73 percent of all oncologists, Mrs. Wolf's oncologist never had a discussion with her about dying (Mack et al. 2012). And like most Americans with lung cancer, Mrs. Wolf did not hear any mention of hospice by any of her doctors until two months before her death, even though hospice has been cited for fifteen years as the best way to die (Smith and Schnipper 1998). Her radiation oncologist was not forthcoming with any realistic results, downplayed the toxicity of radiation, did not formally estimate—or more likely overestimated (Chow et al. 2005)—her potential longevity, despite the availability of simple predictive tools (Chow et al. 2008), and disparaged hospice as drugging people with opiates and killing them off sooner. In fact, hospice has consistently been associated with longer survival in lung cancer patients (Connor et al. 2007; Saito et al. 2011). None of Mrs. Wolf's doctors ever consulted a palliative care specialist, despite growing evidence that people who use palliative care along with the usual oncology better understand their disease and the goals of their treatment, use less IV chemotherapy in the last sixty days of life, and live longer (Temel et al. 2010, 2011); in fact, palliative care is now recommended as standard care by the American Society of Clinical Oncology (Smith et al. 2012).

The part of me that is a health service researcher, economist, and guardian of Medicare resources also is dismayed. Mrs. Wolf had unnecessary PET scans; discussed radiation or surgery to remove liver metastases based only on preliminary results from a few uncontrolled trials, with no high-level evidence to suggest benefit; and cost Medicare, insurers, and her family $177,435 in her last eighteen months of life. Although her share was $25,000, at least she had Medicare, the most bankruptcy-protective form of insurance (Ramsey et al. 2013). By my estimate, at least 10 percent of Medicare funds are spent in that last month of life, which is 40 percent of the 25 percent consistently spent in the last year of life (Lubitz and Riley 1993; Riley and Lubitz 2010). At least Mrs. Wolf used hospice, which, in addition to better symptom management and possibly longer survival, saves Medicare about $2,600 per person by keeping people at home and comfortable (Kelley et al. 2013), and not in the hospital. But now that physicians are ethically supposed to be faithful stewards of the medical commons (Snyder 2012), was her money spent in the best way for Medicare patients? Absolutely not. Erlotinib has minimal, if any, activity in patients like Mrs. Wolf, who was never tested for EGFR-activating mutations, so Medicare could have saved $4,000 a month in drugs, scans, and toxicity (Keedy et al. 2011). Did she need another PET scan to show that there were eight rather than five lesions in her liver and thus was not a candidate for liver resection or lesion ablation? No.

I don't think we should let the family and patient off the hook too easily, either. Mrs. Wolf was told by at least two oncologists that her cancer could not be cured, but she continued to pretend otherwise. No matter what oncologists try—even very explicit Decision Aids stating that death is certain and should be planned—about 20 to 30 percent of patients resolutely insist that they can be cured (Smith et al. 2011). Did the patient do any advance care planning about decisions near the end of life, such as where she wanted to die or whether she wanted hospice involved? Did the patient and family ever request extra time to discuss the future and predictable events, or did they just squeeze it in during her usual cancer appointments? Paradoxically, proposals allowing Medicare to pay for such discussions helped produce the misleading "death panel" charges when the Affordable Care Act was being drafted. Now, however, even a conservative like the retired Republican senator (and cardiac surgeon) Bill Frist maintains that it is our patriotic duty to document these choices, because avoidant behavior and high end-of-life expenses in the current system will bankrupt us (Frist 2012).

Finally, where did Mrs. Wolf's primary care physician go? There is evidence that when family physicians are involved at the end of life, patients' quality of life is less bad and has less distress (Aubin et al. 2011). Here, the primary care physician who made the diagnosis was kept out of the picture until he was needed to provide the appropriate push to get Mrs. Wolf into hospice. But could he have helped more with the agitation and delirium, and the mucositis? Often, tiny amounts of antipsychotics like haloperidol (Haldol) can fix delirium (Hui et al. 2010), though some delirium cannot be fixed. And could he have called for a palliative care consultation earlier, instead of the usual late or never that we so often observe? Instead, he diagnosed a cancer when it was asymptomatic but later would have presented with painful liver mets, spine mets, or a seizure from the brain mets. The eventual course would have been the same.

What could have, and should have, been done differently? Where to start.... First, I do not blame the family physician for his early diagnosis, but thank him for being a consistent honest voice, and wish that he had been more involved, especially in the management of delirium near the end. Second, oncologists should have some quality imperatives to help them treat according to guidelines. In fact, quality improvements, based on guidelines, already are in place that should mandate EGFR testing before prescribing erlotinib (Tarceva), the $4,000-a-month pill. The American Society of Clinical Oncology's Quality Oncology Practice Initiative (QOPI) has good benchmarks for this and for things like "referral to hospice" and "length of stay in hospice" that the oncologist might have used. This QOPI is voluntary, however, and most practices will not follow it until it is mandated. Mrs. Wolf's family also intimated that oncologists offer chemotherapy in order to make money—and we do make money sometimes—but the situation at the end of life is different. The percentage of people receiving chemotherapy in the last month of life is remarkably similar worldwide (Braga 2011; Kelly and Smith in press), regardless of any profits, suggesting that patients do not want to die, that their perspective differs from that of well people who are not staring death in the face, and that oncologists do not have the skills to make the transition to hospice (Matsuyama, Reddy, and Smith 2006).

Third, we oncologists need to learn new skills at communicating increasingly complex choices. We have been advocating the "ask, tell, ask" method not just at the initial diagnosis but at every transition point, such as the diagnosis of recurrence, new metastases, and progression of disease. The simplest and most effective approach is to be honest and to state explicitly that we will not abandon the patient (van Vliet et al. 2013). An example of this approach is, "Medicine cannot cure you of this. The average person lives about eight months once the disease comes back, sometimes longer and sometimes *shorter*. But we will be with you every step of the way." We can use Decision Aids to adequately represent treatment effectiveness and toxicity, just as we routinely use these aids for breast cancer. A simple start is the American Society of Clinical Oncology's recommended practice of having a hospice information visit for patients who have three to six months to live, to emphasize that hospice will be needed, and to make the eventual transition smoother. We need to recognize that not all our patients are going to do better than the average and to explain the real circumstances to them so that they can have a "good planning panel" session (Smith and Bodurtha 2013) to discuss wills, living wills, CPR, hospice, and legacy creation as ways to preserve their dignity (Chochinov et al. 2011).

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