

# WHY A TOP CANCER CENTER COULD SAVE YOUR LIFE

BY SHARON BEGLEY ON 10/16/09 AT 8:00 PM

## CULTURE

Like everyone else who isn't comatose, Sara Sussman had heard over and over that America has the best health care in the world. So she still can't believe what happened to her. She found a lump in her breast two days before Christmas last year, and a mammogram found something that, the radiologist told her, should be biopsied. But he didn't tell her where to do that. Sussman, then 35, asked her ob-gyn for a referral to the Johns Hopkins Kimmel Cancer Center, near her home in Maryland. She refused: "Girls your age don't get breast cancer," she said, and referred Sussman to a general surgeon at a hospital with no cancer center. Sussman instead called a New York University oncologist who had treated her father and brother for melanoma, and saw him that week. Looking at the same films that the "girls your age don't get breast cancer" ob-gyn had dismissed, he immediately spotted two tumors—both so large as to be inoperable. Sussman had inflammatory, stage IV breast cancer, which had metastasized to her hip. She has now had six months of chemotherapy to shrink the tumors, has started radiation, and is facing two surgeries.

This is not a story about medical mistakes. It is about wide disparities in cancer diagnosis and treatment. The consequence of these disparities is that although America indeed has some of the best cancer care in the world, there is no guarantee that any particular patient will receive it. Worse, in trying to find the oncologist or cancer center with the best track record on, say, stage IV bladder cancer, even the savviest patient quickly hits a wall: with a few exceptions, cancer centers treat these "outcomes" data like state secrets.

When we began asking if it matters where a patient gets treated for cancer, we were agnostic on whether disparities in diagnosis and treatment between elite hospitals and all the rest were great enough to affect survival or quality of life. After all, some tumors are so non-threatening, and their treatment so standard, that it shouldn't matter where you go; your chances are pretty good. Five years after mastectomy, for instance, 81 percent of women treated at the top cancer centers are alive, compared with 77 percent of those treated elsewhere—not a huge difference. Similarly, at Fox Chase Cancer Center in Philadelphia, to pick one top site, the five-year survival rate for patients with stage II prostate cancer is 93 percent, compared with 88 percent nationwide. "Eighty percent of cancers can and should be treated in community settings," says urological surgeon Derek Raghavan of the Cleveland Clinic. "I've seen 2,000 cases of testicular cancer," whose treatment is straightforward, "but that doesn't mean I give better chemotherapy than someone who has seen 30." At the other end of the severity spectrum, Ted Kennedy was treated for glioblastoma at Duke Comprehensive Cancer Center, one of the nation's best. He lived 15 months after his diagnosis. The median survival for glioblastoma is 14.6 months. Against some cancers, even the medical gods are helpless.

But then experts drew our attention to the millions of cancers in the middle—those that are neither hopeless nor straightforward (or as straightforward as cancer can ever be). After we interviewed dozens of oncologists, pored over published papers, and obtained outcomes data that cancer centers have never before made public, it became clear that for these cancers there are indeed significant outcome differences depending where you are treated. "There is clear documentation that not all Americans get the best cancer care, even though it is available," says cancer surgeon Stephen Edge of Roswell Park Cancer Institute in Buffalo, N.Y. "We definitely have wide variations."

First, there are differences between the nation's top cancer centers and the community settings—local hospitals and oncologists in private practice—where 90 percent of cancer patients are treated. Five years after surgery for prostate cancer, for instance, 72 percent of men treated at leading hospitals are alive, compared with 62 percent of those treated elsewhere. Scrutinizing data from specific cancer centers reveals even greater gaps. Five-year survival

for stage IV prostate cancer is 71 percent at Fox Chase, for instance, but 38 percent nationally. For stage IV breast cancer, the respective figures are 28 percent and 19 percent—an almost 50 percent edge. For stage IV cervical cancer, five-year survival is 33 percent at the Cleveland Clinic vs. 16 percent nationally. Remarkably, the quality-of-care gap between elite centers and community settings doesn't reflect who has the newest, coolest multimillion-dollar machine, in which case one could forgive small community hospitals for lagging behind. Instead, it comes down to such basics as experience; to getting the diagnosis right; to whether doctors address diet, exercise, and psychological health; to whether doctors routinely test tumors for molecular markers that can guide therapy; to whether care is coordinated or haphazard; to how well doctors monitor patients—after surgery, radiation, or chemo "got it all"—in order to minimize the chance that the cancer will recur. And it reflects a knowledge gap. Because so many doctors don't seem to know that breast MRIs are influenced by the menstrual cycle, says oncologist Julie Gralow of the Fred Hutchinson Cancer Research Center in Seattle, about 15 percent of the diagnoses for which she provides a second opinion are wrong.

Second, there are differences *among* the top cancer centers. To take one example, at Memorial Sloan-Kettering Cancer Center in New York, slightly fewer than 40 percent of patients operated on for esophageal cancer are alive five years later, compared with about 30 percent for other top hospitals (and just 10 percent for other New York City hospitals). Even at the elite cancer centers, surgeons differ in their skill at operating on a prostate that has been ravaged by radiation, and doctors differ in their ability to manage the side effects of chemotherapy. These gaps affect who will become one of the 562,000 Americans who will die of cancer this year.

But if a patient is motivated enough to set her eye on being treated at one of these top centers, she might as well print out a list, tape it to her wall, and throw darts: she hasn't a prayer of learning which have the best records with particular cancers. The Cleveland Clinic is the only one that makes its detailed outcomes data available to the public, on its Web site. For the most part, then, if you want to find whose patients with stage IV colorectal cancer hang on the longest, you're out of luck. "When it comes to trying to compare institutions by

outcomes," says Len Lichtenfeld, deputy chief medical officer of the American Cancer Society, "there is no readily accessible way for patients to do that." When we asked to see Sloan-Kettering's outcomes data, we had to promise not to copy any documents. A spokesperson for M.D. Anderson Cancer Center in Houston said, "We do not have outcomes data at this time," while a physician there explained that doctors don't want to release data "that's difficult for people to interpret." And although the National Comprehensive Cancer Network (NCCN) of the nation's 21 top cancer hospitals collects data on how well its members adhere to treatment guidelines, it will not release the information on specific centers.

The near impossibility of learning a cancer center's record is especially problematic given the striking disparities in guideline adherence even among the top hospitals. In dozens of studies since 1997, scientists have collected data on how well NCCN members follow treatment guidelines. A 2008 study, for instance, measured how often patients were given tamoxifen after breast-conserving surgery, which reduces the chance that cancer will recur in that breast or appear in the other; it varied from a low of 34 percent of patients in one comprehensive cancer center to 74 percent in another. Similarly, the number of patients receiving recommended chemotherapy for colon cancer ranged from 17 percent to 64 percent at eight top cancer centers. There can be good reasons not to give chemo to a patient with stage II colon cancer, but it is unlikely that those reasons vary by a factor of almost four from one hospital to another.

Although the researchers did not analyze whether these disparities among top cancer centers affect patient survival, Edge of Roswell Park points out that the guidelines are guidelines precisely because studies show they keep patients alive. The difference between a compliance rate of 80 percent and 90 percent in some breast-cancer guidelines, for instance, works out to 2,000 more women staying alive every year. "But to find top-quality care, let alone learn which places are following treatment guidelines," he says, "patients are totally dependent on hearsay."

Or on the kindness of strangers. Oncologists and others who treat cancer know who's the best, as Don McKay learned. In December 2004 he rushed his 18-month-old son, Kyle, suffering from lethargy, an excruciating headache, difficulty walking, and vomiting, to the emergency room of a local hospital on Long Island. A CT scan discovered a brain tumor. The surgical resident warned McKay and his wife against moving Kyle, and explained that the boy would require more tests and, in all likelihood, surgery. As McKay and his wife were reeling from all this, a nurse pulled him aside. "Look at me," she said. "Don't you want the best pediatric brain surgeon on the East Coast for your son? Then you want Dr. [Jeffrey] Wisoff of NYU." Wisoff, who is known for undertaking surgeries that others won't even attempt, took the case, and Kyle was transported to NYU, where he had six-hour surgery to remove a medulla blastoma, followed by six months of chemotherapy. Today Kyle is cancer-free. The surgery spared all of his healthy brain tissue.

Not surprisingly, outcomes for complex surgeries like Kyle's show the greatest disparities between top cancer centers and community hospitals. "It's complicated diseases, like esophageal, pancreatic, and hemallogic [blood] cancers [which can require bone-marrow transplants], that should be treated at NCCN centers," says Edge, who chairs the commission on cancer of the American College of Surgeons and has led efforts to measure the quality of cancer care. For esophageal cancer, the mortality gap is alarmingly wide: 17 percent for low-volume hospitals vs. 4 percent at high-volume cancer centers, a 2009 study by scientists at Sloan-Kettering finds. Similarly, half of Sloan-Kettering's stomach-cancer patients are alive five years after surgery, compared with 37 percent for both community and other cancer hospitals. "For tough surgeries, you want the guy with steady hands who's been in an impossible abdomen, knows the no-fly territory and what he can get away with," says Raghavan of the Cleveland Clinic. With a slim, otherwise healthy man with testicular cancer, he explains, it's easy to remove a dozen lymph nodes (to check for metastasis and therefore the need for chemo and radiation). But in a 300-pound man with fat everywhere, lymph nodes—and therefore metastasis—can be missed, with consequences that can be fatal. Paradoxically, perhaps, it needn't cost more to be treated at a top cancer

center. They all accept Medicare reimbursement. And it can cost less. Length of stay and rate of complications are both lower at elite hospitals.

For common cancers such as breast, prostate, and colon, however, "the surgery can often be very well done in non-NCCN settings," says Edge, and survival rates are comparable to those after surgery at elite cancer centers. Five years after the nine most common cancer surgeries, for instance, 62 percent of patients treated at the nation's top academic centers are alive, compared with 58 percent of those at local hospitals.

It's definitely a plus not to die on the operating table, or of postsurgical complications. But assuming you survive surgery, does it matter where you receive follow-up care? Most chemo and radiation is given on an outpatient basis, and is so standardized that where you roll up your sleeve for the chemo IV doesn't matter, at least for cancers with an accurate diagnosis and straightforward treatment regimen. Indeed, preliminary data confirm that community hospitals know what they're doing when it comes to cancers with standardized treatments: at elite NCCN hospitals, 96 percent of breast-cancer patients who have had breast-conserving surgery are treated with radiation, as the guidelines call for, while among insured patients at community hospitals in Ohio, says Edge, 97 percent are.

One caveat about community oncologists, however. "Doctors there say there is a lot of art in the treatment of cancer, whereas oncologists at top centers say it's a science," says Lichtenfeld of the ACS. "Art" might sound desirable and even personal—my oncologist isn't blindly following a recipe in treating me!—but it covers a lot of sins, notably the tendency of some doctors to pick treatments that worked for other patients, even when those treatments have not passed muster in clinical trials. (Doctors, like the rest of us, remember their successes, and can be fooled into thinking a nonstandard treatment works when in fact its success was a statistical fluke.) "But for common cancers such as breast and colon, there is no reason not to expect adequate care in a community setting," says Lichtenfeld. "The 'recipes' are well established. Still, it's appropriate for patients to ask, 'Are you following the NCCN guidelines?' It's with less common cancers that you should see someone

with a lot of experience." As Raghavan of the Cleveland Clinic says, "I might pull out of the cupboard a regimen I last used in the 1980s."

Another caveat is that to know which cancers can be successfully treated in a community setting, you must have an accurate diagnosis. Here, unfortunately, the disparities between elite cancer centers and everywhere else can be stark. "About 75 to 80 percent of cancer diagnoses can be done correctly" in settings outside specialized hospitals, says Thomas Burke, physician in chief at M.D. Anderson. He estimates that patients traveling to M.D. Anderson have an incorrect diagnosis from a community pathologist about 5 to 10 percent of the time. Although many of those patients have rare cancers that pathologists have little experience with, some have all-too-common ones. A woman in a small town in Texas recently called Raymond DuBois, executive vice president of M.D. Anderson, after being diagnosed with an eight-millimeter ductal carcinoma in situ, a treatable form of breast cancer. DuBois said it never hurts to get a second opinion, and referred her to an M.D. Anderson oncologist—who determined that she actually had a five-centimeter breast tumor that required "much different treatment than what they were planning," says DuBois. "She required total mastectomy, radiation, and adjuvant [chemo] therapy. I think we saved her life." When it comes to outcome disparities, he says, "diagnosis is where the biggest problem is."

That has long been recognized as the weak link in cancer treatment. As far back as 1997, scientists at M.D. Anderson examined pathology reports for brain and spinal-cord cancers in patients who had been diagnosed elsewhere, mostly in community hospitals. Of 500 cases, there was serious disagreement (meaning it had significance for what therapy the patient should have) in 44, and substantial disagreement (affecting the type or grade of tumor) in another 96. The scientists called these "clinically important diagnostic errors."

Fast-forward 11 years. In an analysis of 731 patients diagnosed with any of five forms of non-Hodgkin's lymphoma, scientists examining NCCN data found "pathologically discordant" diagnoses—that is, the community hospital got it wrong—in 43, or 6 percent. Thirty-five of those misdiagnosed patients should probably have gotten a different therapy. (The scientists were not able to track

outcomes to see if the errors were fatal, but NHL is not a good cancer to have incorrectly treated.) That diagnosis errors persist may not be surprising; pathologists are only human. But it is unfortunate that some pathologists have resisted attempts to standardize terms and techniques. "I would say that 80 percent of the pathology reports I get from community settings are ambiguous or unclear," says breast oncologist Kimberly Blackwell of Duke. "If you tell a woman she doesn't need chemo, but only tamoxifen [because the pathology report erred in assessing metastasis], it's a problem."

At top cancer centers, surgeons, oncologists, and radiologists coordinate care smoothly, so patients get what they need right away rather than waiting weeks between scans, diagnoses, and treatment. At Duke, the wife of a Marine arrived in Blackwell's office earlier this year, having been told that her metastatic breast cancer was untreatable (the doctor, at a community hospital near Camp Lejeune, was kind enough to offer to arrange hospice care). This was not so much an error in diagnosis as an admission of defeat: metastatic breast cancer is a challenge for even the best oncologists, and doctors who have little experience with it sometimes give up before they try. But Blackwell admitted Erin, who is in her 30s, and by the next morning had her liver, brain, and other scans in hand—and could tell the radiation team what to zap. "By 5 o'clock she was on treatment," says Blackwell. "Little delays with a nonaggressive cancer might not matter, but a two-week delay with an aggressive cancer can mean the difference between life and death." That underscores another advantage of top cancer centers: they have a much stronger ethic of trying anything and everything. Often, that does not buy the patient much time, as Kennedy's case tragically shows. But it can buy days or weeks. That doesn't show up in five-year survival data, but can make a huge difference to a patient who gets to celebrate one more wedding anniversary or the birth of a grandchild.

The team approach at top cancer centers brings notable benefits in something that gets second billing in many community settings: managing side effects. The nausea and mouth sores that often follow chemo can make a patient miserable; high blood pressure and kidney damage can require that the chemo be halted. Cancer drugs such as doxorubicin and Herceptin cause heart failure

in 5 to 10 percent of patients, notes cardiologist Edward Yeh of M.D. Anderson, which, like other elite centers, has a full complement of cardiologists on staff. If a patient's heart condition is treated, Yeh points out, he can continue receiving chemo. The other benefit of a team approach is a roomful of minds focusing on each case. At M.D. Anderson, the breast-cancer department alone has 24 medical oncologists, 13 surgeons, seven radiation oncologists, 16 radiologists, and 13 pathologists. "For every new case, 24 medical oncologists sit around the table and discuss it," says Jennifer Litton, one of the 24. "That's 23 second opinions straightaway."

That's great for patients who can get to Seattle, or Philadelphia, or New York, or other cities with top cancer centers. "But obviously not every patient can be treated in Houston," says M.D. Anderson's Burke—or at the 20 other NCCN sites, especially since it can take weeks to get an appointment. M.D. Anderson is therefore forming partnerships with community hospitals to share expertise, an approach the National Cancer Institute is supporting through its Community Cancer Centers Program. NCI has awarded \$5 million to 10 groups to try to bring care everywhere up to the level at the top centers, as by sharing pathology expertise. "Everyone in cancer gets that there are huge disparities in the quality of care between cancer centers and community hospitals," says NCI director John Niederhuber. "We are trying to do something about it."

He made this his cause after his wife, diagnosed with advanced breast cancer a decade ago, had to fly from their home in Wisconsin once a month to be treated at NCI. She participated in a clinical trial there, surviving months longer than expected. When your husband is one of the nation's top oncologists, you know where to go. As for the other 1,490,000 people who are diagnosed with cancer this year, good luck.