

Cancer Patients, Lost in a Maze of Uneven Care

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The first doctor gave her six months to live. The second and third said chemotherapy would buy more time, but surgery would not. A fourth offered to operate.

Karen Pasqualetto had just given birth to her first child last July when doctors discovered she had colon cancer. She was only 35, and the disease had already spread to her liver. The months she had hoped to spend getting to know her new daughter were hijacked by illness, fear and a desperate quest to survive. For the past year, she and her relatives have felt lost, fending for themselves in a daunting medical landscape in which they struggle to make sense of conflicting advice as they race against time in hopes of saving her life.

“It’s patchwork, and frustrating that there’s not one person taking care of me who I can look to as my champion,” Ms. Pasqualetto said recently in a telephone interview from her home near Seattle. “I don’t feel I have a doctor who is looking out for my care. My oncologist is terrific, but he’s an oncologist. The surgeon seems terrific, but I found him through my own diligence. I have no confidence in the system.”

It was a sudden immersion in the scalding realities of life with cancer. This year, there will be more than 1.4 million new cases of cancer in the United States, and 559,650 deaths. Only heart disease kills more people.

Cancer, more than almost any other disease, can be overwhelmingly complicated to treat. Patients are often stunned to learn that they will need not just one doctor, but at least three: a surgeon and specialists in radiation and chemotherapy. Diagnosis and treatment require a seemingly endless stream of appointments. Doctors do not always agree, and patients may find that at the worst time in their lives, when they are ill, frightened and most vulnerable, they also have to seek second opinions on biopsies and therapy, fight with insurers and sort out complex treatment options.

The decisions can be agonizing, in part because the quality of cancer care varies among doctors and hospitals, and it is difficult for even the most educated patients to be sure they are receiving the best treatment. “Let the buyer beware” is harsh advice to give a cancer patient, but it often applies. Excellent care is out there, but people are often on their own to find it. Patients are told they must be their own advocates, but few know where to begin.

“Here it is, a country with such a great health system, with so many different breakthroughs in treatment, but even though we know things that work, not everybody who could benefit gets them,” said Dr. Nina A. Bickell, an associate professor of health policy and medicine at the Mount Sinai medical school in Manhattan.

Death rates from cancer have been dropping for about 15 years in the United States, but experts say far too many patients receive inferior care. Mistakes in care can be fatal with this disease, and yet some people do not receive enough treatment, while others receive too much or the wrong kind.

“It’s quite surprising, but the quality of cancer care in America varies dramatically,” said Dr. Stephen B. Edge, the chairman of surgery at the Roswell Park Cancer Institute in Buffalo. “It’s scary how much variation there is.”

Government and medical groups acknowledge that the quality of care is uneven. In 1999, a report by the Institute of Medicine in Washington said, “For many Americans with cancer, there is a wide gulf between what could be construed as the ideal and the reality of their experience with cancer care.” The institute noted that there was no national system to provide consistent quality.

In March, cancer organizations including the National Quality Forum tried to address the problem by issuing the first set of quality measures that can be used to judge whether hospitals are giving patients up-to-date care for breast and colon tumors, two of the most common cancers.

The list of measures calls for treatments that seem so basic even to a layperson that it is shocking to think any hospital would skip them. For instance, it says that women under 70 who have lumpectomies for breast cancer should also have radiation, and that doctors should consider chemotherapy for people with colon cancer that has spread to their lymph nodes.

Dr. Edge, who worked on the measures, said, “While they’re fairly simple and straightforward, and they seem very basic, it’s quite surprising how many people do not get the care that’s recommended.”

Treatment guidelines approved by experts already exist for 70 to 80 types of cancer (<http://www.nccn.org/>), but the new measures are the first to be formally endorsed by cancer organizations to assess whether hospitals are performing up to par. The measures were developed by the American College of Surgeons’ Commission on Cancer, the American Society of Clinical Oncology and the National Comprehensive Cancer Network, and are available online at www.facs.org/cancer/qualitymeasures.html.

It took more than two years, Dr. Edge said, before experts even agreed on these basic principles. The first goal is to give doctors and hospitals a chance to see how they stack up to national standards. Eventually, the measures may be used by regulators and payers, including Medicare, he said.

First Sign of Trouble

Karen Pasqualetto is slight and dark-haired, with a soft voice that belies how tough she is. After giving birth by Caesarean section last July, she noticed a lump under her ribs. It was the size and shape of a banana. Doctors noticed it but did nothing. She was sent home and was told it was probably a bruise. Within a week she was back in the hospital, terribly ill — swollen with fluid, vomiting, so anemic she needed a transfusion and suffering from severe abdominal pain. Tests found colon cancer that had already spread, or metastasized, to her liver — stage 4, the final chapter of the disease.

“The doctor came in with a tear in his eye,” she recalled. “ ‘It’s bad.’ Those were his exact words. ‘You have maybe six months.’ ”

Surgery was not recommended because the liver tumors were too extensive. She was referred to an oncologist, who offered “palliative” chemotherapy, given strictly to ease symptoms, not to try for a cure.

“His attitude was that it wouldn’t really make a difference,” Ms. Pasqualetto said.

Palliative treatment was all her health plan would cover. But she had read enough about the disease to know that the proposed regimen did not include the full program of drugs typically recommended for stage 4.

Look for other opinions, her family urged. Her husband had a new job that provided better health coverage, and they switched to a different insurer.

“I think I’d be dead if I’d stayed with the first provider,” she said.

Ms. Pasqualetto, a self-described Type A go-getter, knew better than most how to find information. She has a law degree and worked for several technology start-ups. She had made enough money to quit that career and do something she loved, teaching sixth grade at a Catholic school in Seattle.

She rejected the first oncologist after one visit and consulted the well regarded Seattle Cancer Care Alliance and Swedish Cancer Institute. Both recommended aggressive chemotherapy. Surgery might be possible, they said, if the drugs would shrink the tumors enough. She chose an oncologist at the Swedish institute Dr. Philip Gold, who brushed aside her six-month death sentence and assured her that people with stage 4 colon cancer could live three to four times that long.

“His message to me as a patient was, ‘I have a lot of tricks up my sleeve, this is what we start with, and if it doesn’t work I have this, and then I have a clinical study,’ ” Ms. Pasqualetto said. “The feeling I got was, there was hope, and a plan of attack.”

Eleven months later, after 22 courses of treatment, she gave Dr. Gold credit for keeping her alive and giving her extra time with her daughter, Isabel.

Location, Location, Location

Where patients are treated can make all the difference. Some doctors and hospitals may not see enough cases to stay sharp, especially when it comes to rarer kinds of tumors, complicated operations or advanced stages of the disease — all areas in which studies have shown that experience counts. This factor may leave people in rural areas or smaller cities, and poor people, at a distinct disadvantage.

Communication also plays a crucial part: some patients may not understand that surgery alone is not enough and that they also need chemotherapy or radiation or both.

Even when treatment guidelines are based on solid evidence, hospitals or doctors may not stick to them. But sometimes, the science is not clear, and experts do not agree on the best course — or even on whether there is a best course.

“In cancer, there is frequently no one best doctor and no one best treatment,” said Dr. John H. Glick of the Abramson Cancer Center at the University of Pennsylvania.

When patients consult him for second opinions or to transfer their care to his center, Dr. Glick estimated that he and his colleagues concur completely with the original doctor in about 30 percent of cases. But in another 30 to 40 percent of cases, they recommend major changes in the treatment plan, like a totally different chemotherapy regimen or the addition of radiation. Sometimes his team makes a completely different diagnosis.

In about another 30 percent of cases, his team recommends minor changes in chemotherapy, or additional tests. “We interpret things differently, maybe because we have more experience,” Dr. Glick said. “We see hundreds of patients with Hodgkin’s disease. A community oncologist may see only a couple.”

Warning Signs Overlooked

Looking back, Karen Pasqualetto thinks she had cancer symptoms that were dismissed by doctors in 2003 or 2004 — at least two years before the disease became horribly obvious. She noticed blood in her stool, a classic warning sign of colon cancer. But it lasted only a few days, and such bleeding can also be caused by minor ailments like hemorrhoids. Many doctors do not even think of colon cancer in a young person with no family history of the disease, and her doctor said anal fissures had probably caused the bleeding. There is no way now to know whether that was correct. No sigmoidoscopy or colonoscopy was done to examine the inside of her colon or rectum. Other warning signs were also missed or ignored: anemia and blood in her stools during pregnancy and in the hospital after giving birth .

Ninety percent of colorectal cancers occur in people 50 and older — the reason screening generally starts at 50 — but that still leaves more than 15,000 new cases a year in younger people, some of whom have no symptoms.

The sad paradox of colon cancer is that it is often preventable — but not prevented. It is one of the cancers for which screening tests can find cancers or precancerous growths early enough to cure the disease or even prevent it with surgery alone.

Only 39 percent of colon cancers are detected early. The disease is still the second leading cause of cancer death in the United States (lung cancer is first), with about 154,000 new cases and 52,000 deaths expected this year.

Doctors say the main reason the death toll remains so high is that not enough people are screened. Screening is unpleasant: it requires stool tests or scopes inserted into the rectum. It should start at age 50 for most people, earlier for those with risk factors like a family history of colon cancer. But many people refuse the tests or put them off. Some cannot afford colonoscopy, which costs \$2,000 to \$4,000; not all insurers cover it, even for people over 50.

Whatever the reason, only about half of those who should be tested actually are. Deaths could be cut in half, experts say — meaning 26,000 lives a year could be saved — if all those who need screening were to receive it. It is possible that screening tests have saved President Bush from developing cancer. He has had colon polyps removed on several occasions, including last Saturday, when five were snipped out. Most polyps do not become malignant, but they are removed when found because nearly every colon cancer starts out as a polyp.

Screening has no advocate like a patient who has been through it all — surgery, radiation and chemotherapy, or slash, burn and poison, as some people call it — for a tumor that might have been easily cured if it had only been found sooner.

“If people knew what they had to go through with colorectal cancer, they wouldn’t hesitate to have this silly little colonoscopy,” said Rebecca Michalovic, who has rectal cancer that was diagnosed in 2003. Ms. Michalovic, 60, has had the works: radiation, three operations and a half-dozen ferocious drugs. Despite it all, the cancer has spread to her lungs. Even so, she continues to work full time as a counselor and administrator at Daemen College in Amherst, N.Y. But one drug after another has stopped working, and she is down to the last two. She was 56 and had always been healthy when the disease was diagnosed, after she noticed a bit of rectal bleeding. She had never been checked for colorectal cancer.

“I should have done it,” Ms. Michalovic said.

Elation and Then a Setback

One aspect of Karen Pasqualetto’s care has particularly troubled her. She was told that the first few months of chemotherapy had shrunk the liver tumors enough to make them operable, and surgery was scheduled for last January. She was elated, figuring that removal of the tumors was her best shot at staying alive. But in December a hospital review panel known as the tumor board refused to approve the surgery.

“I was adamantly told it was off the table, and I don’t know why,” Ms. Pasqualetto said. Even she, the feisty patient, felt powerless.

“Who is this tumor board, and do they hold the keys to my life?” she asked.

“You feel a total lack of control when you’re in a position like mine,” she said.

Her oncologist, Dr. Gold, who is chairman of the tumor board, said it was a group of doctors who met informally to review cases and decide what treatment would help a patient most. In Ms. Pasqualetto’s case, the board thought chemotherapy would accomplish more than surgery.

“Patients don’t always hear what you’re telling them,” Dr. Gold said.

The decision haunts Ms. Pasqualetto because it soon became clear that her tumors had been at their smallest in January. By March, they were growing again, defying the chemotherapy. She feared she might have lost her best chance.

In May, she said: “I didn’t even think I’d make it to today. The baby is starting to talk. I feel happy to be here for that moment. Next thing, maybe I’ll get to see her walk.”

Last month, she watched her daughter take her first steps.

But she had a severe allergic reaction to a new cancer drug in which she had placed a great deal of hope. With that reaction, another opportunity was gone. It was a huge setback.

The same day she had the reaction, a surgeon who had reviewed her case said he thought he could help her.

“It was almost like life and death in one day,” she said. “I know my chances are dwindling.”

The surgeon was Dr. Michael Choti, at Johns Hopkins, whom her sister had found through a patients’ advocacy group, the Colon Cancer Alliance. He specializes in colon cancer that has spread to the liver. Though the surgery would be difficult and more than one operation might be needed, he told her that she seemed young and strong enough to withstand it.

She was torn. Her oncologist in Seattle hinted that it might be too late to operate, and that surgery could even make matters worse by spreading tumor cells around inside her body. She trusted him, and the thought of leaving his care frightened her.

But she clung to the hope of becoming “cancer free,” and though surgery offered only a slim chance of that, she believed it was her only chance.

“It would almost be easier if there was somebody telling me what to do,” she said. “But there’s nobody saying, ‘This is what you should do.’”

Missing the Right Treatment

Studies suggest that significant numbers of patients miss out on cancer treatments that could prevent recurrence, prolong survival or save their lives.

Among women with breast cancer, 15 to 25 percent who should have radiation do not receive it, and 20 to 30 percent do not take the anti-estrogen drugs that are a mainstay for most patients, Dr. Edge said.

Women miss out for various reasons.

“Because they don’t get referred to the right doctor,” he said. “Or the doctor doesn’t explain things well and they get afraid of side effects. Or they don’t have insurance and the drug costs \$200 a month.”

Race and ethnicity come into play in ways that are not understood. A study published last year in the *Journal of Clinical Oncology* by Dr. Bickell and other researchers assessed how likely a woman who had surgery for breast cancer was to miss out on other needed treatments — drugs or radiation — at several high-quality teaching hospitals. If she was white, she had a 1 in 6 chance of failing to receive the treatment; black, 1 in 3; and Hispanic, 1 in 4.

A second study published last month by the same group suggested that breakdowns in communication played a part: a third who did not receive the recommended treatment had refused it, and another third missed out because of “system failures,” meaning it was recommended but, for some reason, never happened (and in another third, doctors ruled out the treatment for medical reasons).

With pancreatic cancer, one of the deadliest types, people at early stages have a chance of surviving only if they have surgery. But a study released in June by the American College of Surgeons found that 38 percent of patients who were eligible for surgery were not even offered it.

With ovarian cancer, a deadly disease for which inadequate surgery has been proved to shorten a woman’s life, many do not receive the correct operation, which may require the removal of tumors from the intestine, diaphragm, liver, spleen and bladder.

“A third of the women in the United States are not getting the right surgery, not even close,” said Dr. Barbara Goff, a gynecologic oncologist at the University of Washington in Seattle. “We have so many resources, but we still do so poorly with ovarian cancer.”

For complex operations, numerous studies have shown higher success rates if the hospital and doctor have a lot of experience. But Dr. Goff and other researchers have found that 25 percent of ovarian cancer patients are operated on by surgeons who see only one case a year, and 33 percent in hospitals that treat fewer than 10 cases a year. Too many women are operated on by gynecologists or general surgeons, Dr. Goff said, adding that ovarian cancer operations should be done by gynecologic oncologists, who train specifically in cancer surgery. But she also said that many women do not know what kind of surgeon they need, or they cannot get to that surgeon.

In addition, although a major study in 2006 showed that pumping chemotherapy directly into the abdomen, instead of dripping it into a vein, added an average of 16 months to women's lives and the National Cancer Institute endorsed the technique, some oncologists still do not offer it.

Uneven quality persists even in colon cancer, one of the most common types. Dr. Jane Weeks, a professor of medicine at Harvard, said half a dozen studies had found that in stage 3, when tumor cells have spread to lymph nodes, only about 65 percent of patients are given chemotherapy — even though it has been proved beneficial and is recommended for about 80 percent of patients.

Numerous studies have suggested that men with prostate cancer face the opposite problem — too much treatment, which wastes resources and money and needlessly subjects men to the pain and risks of surgery or radiation.

Prostate cancer, particularly in older men, often grows so slowly that men can be treated with “watchful waiting,” which means monitoring the cancer and treating it only if it starts to grow rapidly or turns more aggressive.

But a study last year of records of men treated from 2000 to 2002 found that among 24,405 with cancers considered to be of relatively low risk, 10 percent were overtreated with radical surgery, and 45 percent with radiation.

The surgeon's expertise is crucial in prostate cancer. A study published this month in *The Journal of the National Cancer Institute* found that the cancer was less likely to come back in patients whose doctors had performed 250 or more operations. Their recurrence rate was 10.7 percent, compared with 17.9 percent in men whose doctors had performed the operation only 10 times.

A Plan for Action

On June 17, a Sunday, Karen Pasqualetto, her husband and Isabel caught a red-eye flight to Baltimore. Ms. Pasqualetto made a point of bringing Isabel, 11 months, to her first appointment with Dr. Choti, hoping that the baby's blue eyes and cheerful grin would remind him just how high the stakes were and inspire him to try even harder to save her.

She emerged from the meeting a bit wistful. Though Dr. Choti had not criticized her previous care, he did say he would have operated much sooner, after a few months of chemotherapy.

In an interview, Dr. Choti said that Ms. Pasqualetto was a borderline case because the liver tumors were so extensive, and he could understand why the doctors in Seattle had decided not to operate.

Laughing as Isabel tottered around a hotel room in Baltimore, Ms. Pasqualetto looked so healthy it was hard to believe she was not. Only her stubbled scalp, mostly hidden by a bright pink ball cap, gave her away.

“I have fears about dying and about getting sicker, but I don’t explore them, except maybe 10 percent of the time,” she said. “The rest of the time, I just think it will all work out. I don’t know what that really means.”

If all the tumors could be removed, she might not even need more chemotherapy.

“Think of what a perspective I’d have on life,” she said. “I don’t allow myself to go there.”

‘A Complex Operation’

“They got them all,” Ms. Pasqualetto’s husband, Chris Hartinger, said shortly after her operation ended on June 21. “It turned out to be five tumors.”

Four were in her liver. The one in her colon was the size of a tangerine. Dr. Choti operated for eight hours, removing 12 to 18 inches of intestine and about 70 percent of her liver.

The day after surgery, Dr. Choti said, “I think we got away with quite a complex operation.”

The tumors were gone, but metastatic disease can be tough to beat in the long run.

“Roughly a third of patients will remain cancer free for a long time,” Dr. Choti said. “About half will still be alive after five years. In a minority, there’s a long-term cure. In some, we turn it into a chronic disease, if you will. She may recur, and we might be able to reoperate. We can prolong survival significantly.”

A few days after surgery, Ms. Pasqualetto was walking laps around the hospital corridors, thinking about things she had not allowed herself to consider, plans she had not dared to make, like whether Isabel would someday like to have a horse.

“I can’t believe it,” she said. “This is pretty exciting.”

But weeks later, at home again, she found herself back in the trenches, unsure of what the next step in her care would be. Her oncologist refused to see her until he spoke with the surgeon, and yet neither of them had called the other. Meanwhile, she was trying to decipher a worrisome report indicating that a CT scan had found minute lesions on her spleen.

“It’s like I’m flapping in the wind,” she said.

Far From Typical

Karen Pasqualetto is exceptional not only for her determination and confidence in dealing with problems that would intimidate many other people, but also for her financial wherewithal. So far her treatment has cost more than \$400,000, almost all of it covered by health insurance from Starbucks, where her husband works in disaster-response planning.

When she joined a cancer support group, she recalled, “It was amazing to me the different experiences people were having based on what they could afford or who their provider was. I was able to say, ‘If the provider won’t pay, my family will. I don’t care, I’m going for a second opinion.’ ”

In the support group, it saddened her to hear other patients with advanced disease take the word of a single oncologist, because she believes that if she had done that, she would already be dead. She has come to think that survival may depend on money and access, and, she said, on “your own drive and motivation — are you Type A? — your education and your ability to sort through the medical world and the insurance world terminology.”

Ms. Pasqualetto’s doctors have accepted her insurance payments, but if they had not, she said, “I would find resources. I would get people to pay. I do have resources. I have access to people who wouldn’t sit by and let me die because of \$200,000.”

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