

FEATURE STORY

Power to the Patient

BY MARC SILVER

Doctors and patients confront shared decision-making.

Julia Reichert is breaking hospital rules. She dares to use her cell phone in her room! But the nurses who walk by don't say a word. How could they? Pierluigi Porcu, MD, an oncologist at Ohio State University's Arthur G. James Cancer Hospital, is in the room with her (as is her partner and their grown daughter). Via the cell phone's speaker device, the four are powwowing with a lymphoma expert at the National Cancer Institute. It is just one more step in the painstaking search for a plan to treat the huge mass of tumor wrapped around her heart, caused by a rare type of lymphoma. "I do not ever want to look back," she says, "and think maybe I should have gone another way."

Reichert is also breaking the old-school rules of the doctor-patient relationship. Once upon a time, cancer patients dutifully followed doctor's orders. But in the past few decades, rules—and roles—have changed. A growing number of patients make all matters of medical decisions, from which treatment to pursue to how to cope with side effects. Sometimes they do so in partnership with the doctor; sometimes they follow their own instincts. And many, though certainly not all, physicians welcome the change.

Patients and physicians typically see one main reason for increased involvement: the Internet. After her doctor called to tell her she had chronic lymphocytic leukemia (CLL), Wendy Ramsey, 51, of Spokane, Washington, recalls, "I got off the phone, took a breath, turned to my computer and got online."

The Internet can offer a crash course in any cancer, news of cutting-edge treatments and advice and support from members of online cancer communities. "The Internet has revolutionized healthcare," says Matthew Loscalzo, director of patient and family services at the Moores University of California, San Diego Cancer Center. "There are reliable resources seven days a week, 24 hours a day." There are numerous unreliable resources, too. "Patients can be filled with terror and fear and misinformation," he says.

In this new web-fueled era, Loscalzo believes doctors must change the way they

speak to patients. “All too often, the physician starts doing all the talking.” He says a doctor should always begin by saying, “Tell me what you know about your situation.”

But the web doesn't get all the credit for the change. Patients began gaining more information—which leads to more decision-making power—in the 1970s. In the early 1960s, a study published in the *Journal of the American Medical Association* characterized nine of 10 cancer doctors as “never-tellers”—they simply did not inform a patient of a cancer diagnosis because the prognosis was so dire. By the late 1970s, improved survival rates inspired the never-tellers to become news-sharers. In addition, the informed consent movement that took root in the '70s brought more openness, points out Julia Rowland, PhD, the psychologist who directs the Office of Cancer Survivorship at the NCI. The movement brought about the requirement that to sign up for a clinical trial, a patient had to know what was going on.

At times, perhaps a little too much responsibility was placed on the patient's shoulders. Back in the '70s, Dr. Rowland says, a doctor might tell a patient: “Here are your options. Go home and think about them, and tell me what you want.” But research shows that, in general, patients want to receive complete medical information from their doctors and share the decision-making authority with them to create a true partnership. Oncologist Charles Loprinzi, MD, of the Mayo Clinic says, “Hopefully, the doctor can provide a realistic scenario of the treatment options, their risks and benefits.”

Picking a Treatment

“The gold standard is not always clear in the literature for many cancers,” says Cameron Muir, MD, an oncologist who serves as vice president for medical services at Capital Hospice in the Washington, D.C., area. Different doctors might recommend different chemotherapy cocktails at different intervals. Dose-dense chemotherapy, for example, administered every two weeks instead of every three, reduces the risk of recurrence and death for certain breast cancer patients being treated with certain chemotherapy drugs. But some breast cancer drugs may be too toxic for the dose-dense schedule, which remains investigational.

Then again, the best treatment may be no treatment at all. Patients diagnosed with slow-growing CLL, like Ramsey, are often given the option of “watch and wait” if there are no serious symptoms beyond fatigue.

The urgency of making a decision can vary. Sometimes a patient may have several weeks to seek additional opinions. Along the way, patients pick up a new vocabulary, such as “targeted agents” and “clinical trials.” While chemotherapy drugs attack both malignant and normal cells, targeted drugs predominantly kill cancer cells. The past decade has seen a surge in the number of targeted agents being approved and more are finding their way into clinical testing. A patient might consider a clinical trial that measures the effectiveness of a new treatment if standard treatments aren't satisfactory for some reason and the new treatment holds the promise of extending life.

But a patient shouldn't simply decide on his or her own to sign up for a clinical

trial, cautions Deborah Zarin, MD, director of ClinicalTrials.gov. The doctor running the trial is in charge of research, and is not intimate with the particular patient's case. That's why a patient considering a trial should talk with his or her doctor to discuss the trade-offs, and should keep the doctor in the loop. "Your clinician is someone you can call if you're not clear what's happening to you or you want to stop the trial," Dr. Zarin explains.

With so many choices, is it any wonder that one breast cancer patient told her doctor that she considered plastering a bumper sticker on her car: "Honk if you think I should have a mastectomy."

View Graphic: Treatment Decisions

The Doctor's Role

Doctors have their own biases, which can add to a patient's bewilderment. Robert Jefferson, a 63-year-old builder in Oakland, California, says running from doctor to doctor to discuss his prostate cancer made him feel like "a nail hanging out with a bunch of hammers." The surgeons wanted to cut, the radiologists wanted to zap. "I felt I was getting advice that didn't have to do with me as a patient," he says, "but with what the doctors did."

Both surgical and radiation treatments promised a similar positive prognosis for his early-stage albeit aggressive tumor, but the risks of surgery made him nervous. "Sexual dysfunction and incontinence are two things I could live the rest of my life without." Radiation offered its own choices: externally radiating the prostate versus brachytherapy, which would radiate the tumor directly from implanted radioactive seeds. The only catch for Jefferson was that brachytherapy would involve the temporary insertion of about 20 foot-long needles into his prostate gland. He also thought about having neither surgery nor radiation and instead finding "some sort of natural treatment if it were practical."

Jefferson spent six months investigating what to do—his docs told him it was OK to take that much time—and reached a decision after traveling to a cancer clinic in Illinois. The opinion was that brachytherapy was a good plan for his cancer.

A review article in the May issue of the American Cancer Society's journal *Cancer* found that despite new treatment options for prostate cancer, little evidence-based consensus exists among doctors about the most effective treatment. So like Jefferson, newly diagnosed prostate cancer patients must weigh existing information with personal treatment objectives.

Doctors typically offer guidance based on a treatment's track record. "There's usually one option I prefer," says William Read, MD, an oncologist at Moores UCSD Cancer Center. In an ideal situation, Dr. Read says he would point to a study of patients treated with radiation or chemotherapy and say, "After five years, more of the folks who got chemo are still standing." But when it comes to making medical decisions, the real world doesn't always match up with the ideal.

And not every patient wants to be a decision-maker. A 2006 article in the *Journal of Clinical Oncology* reported on interviews with 102 advanced breast cancer patients pondering palliative chemotherapy—aimed at symptom management rather than cure. Thirty-eight percent took an active role in making the decision, 47 percent were passive and 15 percent shared the responsibility with their doctor. In other studies, cancer centers report that older patients are more likely to defer to the doctor because that's the way they were raised.

Dr. Read observes: “Some people are thinkers and some are doers.” If a patient's style is to pepper him with questions or simply follow his recommendations, that's OK. Both create a partnership in his view. What's not fine with Dr. Read is the patient who says nothing. Silent sufferers are “in some kind of denial. They're passively going along,” he says. Dr. Read thinks such patients will not fare well with whatever treatment they receive because they're not likely to tell their doctor when a treatment causes certain side effects—information the oncologist needs to fine--tune the treatment.

Studies on coping strategies show that withdrawal and stoic submission are least effective, and patients should be willing to form a partnership with the doctor. More organizations are introducing patient navigators—social workers, nurses or trained volunteers who steer a patient through the cancer maze. Navigators might give advice on questions to ask the doctor or how to fight back when insurance won't kick in, explains Angelina Esparza, director of survivorship at the American Cancer Society, which is expanding its own navigator program. But a navigator will not tell a patient what to do.

One thing a navigator might suggest: Don't procrastinate. “If you've been to seven consults, sometimes you just need to set a date and decide,” says Dr. Rowland.

The Art of Making Decisions

Anyone can become a cancer expert. That's the lesson Julia Reichert, the lymphoma patient, drew from the eight years she and her partner, Steven Bognar, spent working on *A Lion in the House*, a four-hour film on families from different backgrounds, all dealing with childhood cancer, that aired on PBS in June. “The parents just took it upon themselves to double-check and cross--check and be helpfully skeptical of pretty much everything,” Bognar says. “They would not accept whatever was suggested. After a while, they knew a lot more than some of the younger residents. And it mattered in their kids' treatment. It really mattered.”

Along the way, angst is inevitable. After her stage 3 Hodgkin's disease diagnosis, Antoinette Ramos, 26, saw an oncologist in Los Angeles and was not impressed by his manner. “He didn't even look at me when I walked in the room.” She was not impressed with his opinion, either. He proposed six months of chemotherapy followed by radiation. “Are there other options?” she asked. He said that was it. But that wasn't it for her.

Ramos saw a second doctor in San Francisco who listened to her concerns about the possible long-term effects of radiation and her desire to have more options. He told her of an emerging treatment for her disease available through a phase III clinical trial: the Stanford V regimen. Seven different drugs are administered in

rotation, once a week for three months (the standard chemotherapy mix for Hodgkin's disease is given every other week for six months). The hope is that Stanford V is as effective but with fewer long-term side effects. But she still had to choose between the two chemotherapy regimens.

"I had many sleepless nights," Ramos says. She read reports online and scoured through studies. Out of desperation, she asked the oncologist: "What would you tell your own daughter to do?" His answer: Stanford V. "That sealed the deal for me," Ramos says. "He's got a more educated gut feeling than I do, and that's what I want to know." She entered the trial and was in the treatment group that received the Stanford V treatment. And she never looked back. "The doctor said no matter what you choose, you have to believe that if something goes wrong, it would have gone wrong with the other treatment, too," says Ramos.

Many patients ask a variant of her question. It can be tremendously reassuring to hear a doctor say, "This is what I would do for my family member." But the patient is not the doctor's family member. Dr. Rowland suggests reframing the question: "Given what you know about me and my interests, what would you recommend, taking into consideration my clinical characteristics and what's important to stem my anxieties?"

Patients must also learn to listen to their own inner voice. At first, Reichert thought she wanted the most aggressive treatment possible. It finally took one of her doctors to say, "You don't just want the strongest, you want what's best." Reichert realized what she really wanted was the most effective treatment for her, not the "strongest blunt instrument."

Reichert ultimately realized that picking a treatment is bound up in the process of picking a doctor. Reichert, who lives in Yellow Springs, Ohio, initially saw a lymphoma specialist at the James hospital, about an hour's drive from her home. In the quest for the best treatment, she and her family spoke to experts at NCI, M.D. Anderson in Houston, Johns Hopkins Hospital in Baltimore and Northwestern University in Chicago. Her style was total immersion. "I'm a reader and a studier," she says. Papers were typically scattered across her hospital bed. At one point, she asked Dr. Porcu, her James hospital doctor, if she was getting too much information. He replied, "I don't think you've hit the saturation point yet." But there are warning signs of information overload: tense body language or asking the same question at each visit, despite the doctor's best efforts to answer it.



Julia Reichert (center), with her partner Steven Bognar and their daughter Lela, took the lead in choosing the best treatment for herself. Photo by Annie Reichert.

Although Reichert was not overloaded with information, she was definitely overwhelmed. She had reached the point where she had to make a decision. And there was no consensus among the doctors about chemotherapy. CHOP was the standard chemotherapy for lymphoma, but another available treatment called HyperCVAD involved giving more than one treatment per day, known as hyperfractionated. A chemotherapy regimen known as EPOCH had the basic elements of CHOP plus one more drug, and was infused at a slower pace than CHOP. Reichert and Bognar thought of it in terms of a lawn sprinkler: Perhaps running the sprinkler longer with less water pressure would give a better soak than a short, high-pressure cycle. Early word from a randomized trial pitting EPOCH against CHOP was positive for the new chemotherapy regimen, but there weren't yet any data to examine. "That was the scariest part, realizing the responsibility was ours," says Bognar. "That we weren't going to get a golden bullet."

Reichert made up her mind which regimen to select. Then she separately asked Bognar and their daughter, Lela, herself a cancer survivor, what they thought. Although Reichert would have stuck to her wishes no matter what both thought, the decision was unanimous: trust in EPOCH. In retrospect, she says, the real turning point was when she stopped thinking of the oncologist at the James hospital as her adviser and started thinking of him as her doctor. But then who made the decision: Reichert or her doc? "It was sort of like going down a rapid on a raft with them," Dr. Porcu says. Asked who was steering, he replies, "I don't know." Then pauses and adds, "We were all steering a little bit."

Inescapable Uncertainty

It can be a tremendous relief for both patient and doctor once they settle upon a treatment plan, but in the world of cancer, the certainty of a decision carries a measure of uncertainty. Patients come to understand what oncologists have always known: The treatment may or may not be effective. But in all cases, it is important to make decisions with confidence.

Consider the case of Peggy Goode, of Fairfax, Virginia. The fatigue she was feeling in 1999 led to a diagnosis of CLL. Watch and wait is the philosophy for CLL, and her doctors thought she might never need treatment. But by 2003 her fatigue worsened and her white blood cell count jumped. It was decision time. "I trusted my doctor in his experience and expertise," says the 56-year-old. "And he trusted me to tell him what I wanted."

What she wanted was treatment. Her doctor prescribed a chemotherapy drug and a monoclonal antibody—a lab-created protein. Within a week, she felt better. But after six rounds of treatment, a bone marrow biopsy showed only partial remission. Her doctor mentioned the option of an investigational monoclonal antibody that would be injected rather than infused.

Goode mulled. Her doctor gave her an article to read about a study of the drug's effectiveness. Only nine people participated—not enough to satisfy her. She also wanted “a break” from treatment, and was hopeful that promising treatments might be coming in the future. So she passed on the drug.

While her husband and children didn't agree, Goode says she knows her own mind. She first met her husband 35 years ago on a blind date. The two became engaged after 12 days and married after two months. “Somebody told me I'd make a good surgeon because I'm decisive,” she says. In the 21st century, that turns out to be a vital trait not only for surgeons but for patients as well.