

Awash in Information, Patients Face a Lonely, Uncertain Road

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Nothing Meg Gaines endured had prepared her for this moment. Not the six rounds of chemotherapy for ovarian cancer that had metastasized to her liver. Not the doctor who told her, after Ms. Gaines was prepped for surgery, that he could not operate: a last-minute scan revealed too many tumors. "Go home and think about the quality, not the quantity, of your days," he said.



Not the innumerable specialists whom Ms. Gaines, then 39 and the mother of two toddlers, had already mowed through in her terrified but unswerving effort to save her own life. Not the Internet research and clinical trial reports, all citing the grimmest of statistics. Not the fierce, frantic journey she made, leaving home in Wisconsin to visit cancer centers in Texas and California.

Now, just about out of options, Ms. Gaines faced an excruciating decision. Her last-ditch chemotherapy regimen did seem to be working. Three medical oncologists thought she should stick with it. But two surgical oncologists thought she should first try cryosurgery, injecting liquid nitrogen into the tumors to shrink as many as possible, and then following up with chemotherapy, allowing it to be more effective.

The catch? Ms. Gaines's chances of even surviving the procedure were uncertain.

"Who will decide?" she asked a surgeon from Los Angeles.

The doctor then recited what has become the maddening litany of medical correctness: "We're in the outer regions of medical knowledge," he said, "and none of us knows what you should do. So you have to make the decision, based on your values."

Ms. Gaines, bald, tumor-ridden and exhausted from chemotherapy, was reeling. "I'm not a doctor!" she shouted. "I'm a criminal defense lawyer! How am I supposed to know?"

This is the blessing and the burden of being a modern patient. A generation ago, patients argued for more information, more choice and more say about treatment. To a great extent, that is exactly what they have received: a superabundance of information, often several treatment options and the right to choose among them.

As this new responsibility dawns on patients, some embrace it with a sense of pride and furious determination. But many find the job of being a modern patient, with its slog through medical uncertainty, to be lonely, frightening and overwhelming.

Many prostate cancer patients can choose a passive treatment, like watchful waiting, or a more aggressive therapy, like radiation or surgery; each has differing risks and different patterns of side effects. Women with breast cancer often hear conflicting advice from the experts: lumpectomy or mastectomy? Some patients with heart disease can be told by one doctor that they need a bypass, by another that they need angioplasty and by a third that drugs would be just fine. Infertility patients face a blizzard of options.

Such quandaries do not apply only to life-rattling illnesses. Last summer, with the second joint of his left big toe painfully throbbing from gout, Carl Schneider, a law professor at the University of Michigan who had already consulted his internist and a rheumatologist, leaned wearily against a hospital wall as three other doctors argued over which regimen he should follow. One doctor handed him a 20-page Internet printout that cited gout treatment studies, none of them definitive.

"At 57, it's a little late to be starting medical school," Mr. Schneider remarked acidly. "But the burden still falls on me, having to pick among opinions."

The job of being a modern patient includes not only decision making, of course, but often coordinating doctors, medical records and procedures, as well as negotiating with insurance companies, who are often the ultimate arbiters over which treatment options will be covered.

As Ms. Gaines was being treated for cancer she had to wage such a battle. Before she had her diagnosis, her H.M.O. gynecologist laparoscopically removed what appeared to be a cyst on her ovary. But during the procedure, the cyst, which turned out to be a malignant tumor, burst, sending cancer cells into her abdomen. She then wanted to be treated by a specialist, but her insurance plan did not have a gynecological oncologist on its roster. So Ms. Gaines spent months fighting to transfer her care to an out-of-network doctor. Finally the insurers relented, but only after the specialist agreed to perform her surgery at the H.M.O.'s regional hospital, not his own.

Like many patients, Ms. Gaines did not turn to a primary care doctor to help coordinate her care or aid with decisions. Increasingly, that soul-healing doctor-patient relationship has become harder to sustain. Whipsawed by insurance plans, patients frequently switch physicians. Pressed by diminishing reimbursements, those doctors are building ever larger, more unwieldy practices, with less time for each patient.

The strain has left doctors themselves feeling exhausted, angry and heartbroken.

"My visits are almost ludicrous," said Dr. John Russo, an internist in West Orange, N.J., who sees 5,000 patients a year. "But economically you have to see so many more patients than you should, just to keep the lights on. You can't sit and talk and really get an entire history. So you do what you were taught as a resident: do more tests, don't spend more time with patients, getting to know them."

Ms. Gaines was out of time. She had to make a decision. She felt the chill of mortality and the full weight of nearly a year of drastic operations, blood clots, a punctured lung, chemotherapy, research, traveling, countless specialists and unanswerable questions bearing down on her.

"Who's in charge here?" she thought that night, wishing someone would just issue her marching orders. "Oh. I am."

When Doctor Knew Best

A generation ago, most of the diagnostic tests that monitored Ms. Gaines's cancer did not exist. Nor did the range of treatments. After the cancer had been found, most likely her primary care doctor or local oncologist would have told her what to do. And Ms. Gaines would have obeyed.

Until the late 1960's, patients perceived doctors, then almost exclusively white men, as unassailable figures of authority. They knew best. But during the social and cultural upheaval that ushered in the women's rights, civil rights and consumers' rights movements, the paternalistic authority of the physician became deeply suspect. Women fought to join the conversation. Challenging the mystification of medicine, the Boston Women's Health Book Collective published "Our Bodies, Ourselves," a landmark guide. Women changed conventional wisdom about the prevalence of hospital deliveries, hysterectomies and mastectomies.

With the introduction of Medicaid and Medicare in 1965, health care began to be seen as a right, not a privilege. Patients repositioned themselves as consumers of health care, entitled to as much information as possible. Support groups sought to empower patients with booklets and questions for doctors.

In response, many patients became insatiable consumers of medical information. In a New York Times/CBS News poll of 1,111 adults in February, 44 percent of patients who received a diagnosis sought additional information about their treatment from sources others than their physicians, including the Internet, friends and relatives, and other doctors.

Although the push has been on for patients to become more knowledgeable about their care, as they read unfiltered information, they can become more flustered. Shauntel Anderson, 24, a baby sitter in the Bronx who learned she had cardiac arrhythmia, had to choose between continuing her medication or being hospitalized for a procedure known as a catheter ablation.

"I did research for two or three weeks," Ms. Anderson said. "I went to 15 or 20 Web sites because I needed to know everything they were going to do to me. But the Web was messing me up: I got confused because I didn't understand it." Her cardiologists then suggested a few helpful sites. She chose the ablation.

The drive among patients to become better informed has been fueled, in part, by the array of options that often accompanies diagnoses, many so new that gold-standard treatments, backed up by randomized trials, have yet to emerge.

But hope is a potent elixir. Patients with good insurance or other financial resources have quickly learned how to find medical centers that could offer them the latest procedures, like the cryosurgery Ms. Gaines sought out, which had no long-term experience behind it at the time.

A patient's research does not have to be any more extensive than turning on the television. The eruption of pharmaceutical advertising has introduced millions to medical conditions that were once discussed only in the privacy of a consultation, and to the promises of new approved treatments. And inevitably following these promises is the prompt: "Ask your doctor."

At the same time, medical science itself is widely perceived to be in a Renaissance period. Basic research in fields like biotechnology has received deep bipartisan federal support. As the results continue to unfold, patients with major and minor health problems can choose from a fresh array of options: some good, some bad, some redundant and some virtually miraculous.

In the Times/CBS poll, slightly more than half the patients who received a diagnosis were given multiple treatment options. One-third made the decision on their own, with those between the ages of 45 and 64 most likely to do so.

Whether patients make a decision by themselves or at the behest of a doctor, the fact that the choice is theirs has become known among bioethicists as patient autonomy - the right of governance over one's own body. The term is symbolic of the pendulum swing away from the paternalism common through the 1960's. Patients began seeking second and even third opinions.

Floyd Allen, a social worker with CancerCare, a support organization, says that the prostate cancer patients he counsels become exasperated: "For the people who have insurance, they're angry about having to shop around for opinions, and the folks on Medicaid are mad because they can't afford to shop around."

By the 1980's, opinion seeking could even turn into doctor-shopping for specific procedures. Patients started suing doctors, an escalating conflict leading to, among other things, high malpractice premiums, Congressional debates and, in the examining rooms, overcautious conversations between litigation-alert doctors and patients.

Within the past decade, the shift in the doctor-patient conversation - from, "This is what's wrong with you, here's what to do," to "Here are your options, what do you want to do?" - became all but complete. Baby boomers had gotten what they had asked for. And then some.

"People want to feel a part of their health care," said David Mechanic, a medical sociologist at Rutgers University. "But they don't want to be abandoned to making decisions all on their own. When a doctor says, 'Here are your options,' without offering expert help and judgment, that is a form of abandonment. "

The Doctor Is Out

In the 11 years since Rick Sommers received a diagnosis of multiple sclerosis, medical advancements have raised and dashed his hopes, and ultimately led to a schism with his neurologist.

Mr. Sommers, 45, a former marathon runner and New York D.J., went through the shock that many patients experience, after two neurologists determined the cause of his numbness and tingling.

"The doctors are trying to map out exactly what is wrong with you," he said, "and they're giving it to you in sophisticated neurologic terms. It's like being in a foreign country: you don't speak the language, and you're trying to find directions."

Multiple sclerosis is a chronic disease in which the immune system can go haywire and cause neurological disturbances, called exacerbations. The disease can stay dormant for

years at a time, and then flare up. In Mr. Sommers's case, his arm goes dead, and his hand feels like it is on fire.

In 1994, there was a waiting list for the one treatment available. Mr. Sommers became a patient of a leading specialist, and went on a double-blind study for a new drug, not knowing whether he was getting it or the placebo. Over the next two and a half years, he took four pills a day.

"I thought I was being proactive, and I had a fantasy that maybe we were on the cutting edge of something," he said.

He still had the occasional exacerbation, which required rugged outpatient treatment. There was no way to know whether the pills staved off even more attacks. One morning he was in his apartment, paying bills, idly listening to CNBC. The anchor, announcing company news, said that over the weekend, researchers reported that the test drug had flopped. "I slumped in my chair," Mr. Sommers said. "I felt devastated. I spent two and a half years in this study, and this is how I'm finding out it's not working?"

In the years since the disease was diagnosed in him, multiple sclerosis patients have gained access to more information, more specialists and more treatment options. In addition to a phalanx of alternative remedies, at least five drugs that try to prevent exacerbations are on the market. Mr. Sommers has been taking one for the last few years. And he has tried about 10 different medications for symptoms related to multiple sclerosis.

But with all the good news, there is still no cure. Patients can be even more confused, tantalized by the treatments and the plethora of sources of information. Mr. Sommers receives an electronic newsletter from the National Multiple Sclerosis Society, a patient support group, and sets his computer's stock watch for advisories on companies researching drugs.

Early detection for M.S. has improved, which means that more patients are seeking treatment. Clinics are filling rapidly. Mr. Sommers had to make appointments with his neurologist four months in advance.

"It's hard to get a hold of the doctors at the clinic," he said. "My own doctor is so overtaxed. He's pushed, he's pulled, he's torn, he's frantic, he does the best he can. But whenever I saw him, I felt like I was taking up his time. The waiting room has gotten so cramped! There are a lot more hoops to jump through before you can get to the doctor: I got more personal care 11 years ago."

His disease is progressing. He has not been able to run in five years. Sometimes, even walking is hard. But given the stress of going in for a checkup, Mr. Sommers decided to give up on his neurologist of more than a decade. It had been nine months since his last visit.

"I wondered if he thought about me when I wasn't there," Mr. Sommers said. "I wrote a heartfelt note to my doctor to let him know why I wasn't coming back. But I never heard from him."

Even though he recently found a new neurologist, he does not know if this doctor will become the medical cheerleader and adviser that he longs for. "So my gatekeeper is my girlfriend, not my doctor," Mr. Sommers said. "We hash it all out, we figure out the options. She has a good, clear focused head about this stuff."

The Researcher

Last summer, as doctors tried to figure out why her husband's urine had turned the color of cola, Joyce Rich went to work figuring it out herself.

Mrs. Rich, 58, a nursery school teacher from New City, N.Y., had to do something with her nervous energy. Like so many people who, when threatened by illness, feel frightened and helpless, she turned into a formidable Googling machine. Doing the homework gave her the comforting illusion of having a measure of control.

"I can't go into these things ignorant, although in a way I am," Mrs. Rich said. "I would feel as if I just wasn't doing my part."

Mrs. Rich kept meticulous journals of questions and recommended urologists. She made copies of every test result, lugging them to every consultation. "With our luck," she said, "I was afraid they would lose the reports, so I delivered them myself. Besides, I never know if I'm going to stay with the doctor I am seeing, so I make sure I have our records ready for the next one."

Shortly after her husband's illness was diagnosed, she sat trembling in the beauty parlor and confided to her hairstylist, "Ira has kidney cancer!"

Google search: kidney cancer. Results: 10,300,000. And counting.

Her hairstylist called around for referrals. Mrs. Rich's manicurist was particularly helpful: her best friend just had a kidney removed. The manicurist gave her pages of online research.

Mr. Rich, 59, is not robust. He had already undergone open-heart surgery. Removing his kidney laparoscopically was preferable for his overall health. But the tumor was in an atypical location, making the procedure even trickier. Mrs. Rich took her list of doctors to the public library and checked résumés, how often the surgeon had performed the procedure, the number of malpractice suits and their resolution.

"I wasn't aware how often doctors change specialties and narrow their field," said Mr. Rich, a high school guidance counselor. "They do one thing, and then you call them and they're doing something else."

Finally, Mrs. Rich narrowed her list to six. Then, the very process that had helped her feel in control now made her feel more helpless than ever. She had come to the end of her research, with absolutely no idea how to decide. At last she turned to the first place she could have gone and saved herself so much trouble, Mr. Rich's longtime internist. The Riches were lucky to have a doctor willing to be their guide. He did not bother with a menu of options. Without polite shilly-shallying, he gave them just one name.

"It was such a relief," Mrs. Rich said. He sent the Riches to a specialist who was not even on her list. "Cleveland?" Mrs. Rich gasped, "I thought Cleveland comes to New York!"

In retrospect, said Mrs. Rich, who was thrilled with the specialist, "You start this process, and you hope you get all the information you need to make a valid and intelligent decision. But you really don't. And that's where your doctor comes in handy."

So Little Time

With patients having so much medical information, being a primary care doctor these days means donning armor daily. Here comes the public, bearing pharmaceutical brochures, sheaves of Internet printouts, pages of time-consuming questions: Vioxx? Total body scans? Why didn't you recommend a carotid artery Doppler?

Uh-oh, the 11 o'clock news had a three-minute special on pain management. Or the estrogen update du jour. Ask your doctor! The phones will start at 6 a.m., the call-back list will balloon. Inquiring patients will be angry that their calls were not returned.

But besieged doctors first call those with emergencies, then consulting doctors, laboratories, pharmacies, insurance companies and, oh, yes, they also start seeing patients who have scheduled visits.

Doctors feel the benefits and burdens of medical information being so accessible to patients. Yes, studies show that the more informed patients are about their care, the more likely their health will improve.

But the information that patients bring to the office visit is often half-baked. Doctors must spend precious moments in an already constrained time slot re-educating them.

Dr. Russo, the West Orange, N.J., internist who sees 5,000 patients a year, applauds patients who do their homework. But, he noted, especially when patients are researching treatment options, they flop down in his office, feeling inundated.

"The patients are stressed, they're so confused, and it's in our laps," Dr. Russo said. "They are deserving of guidance."

He is the generalist; his job is to diagnose problems. Then he refers patients to specialists who, he hopes, will help them with the daunting decisions.

Patients struggle to find their way, Dr. Russo said, but "there isn't one person to walk them through the process."

It is impossible to overestimate the bracing impact of that old-fashioned guide, the doctor who can be a patient's constant, her Pole Star.

Judy Brown, 46, a community volunteer in Nashua, N.H., who suffers from acute migraines, has tried dozens of preventive and pain-relief medications. Yet she has remained with the same headache specialist, who acts as her primary care doctor, for 17 years. A neurologist with a large patient load who does extensive research, he nonetheless always returns her calls, even when he is on vacation.

"I don't think anyone will cure me," Mrs. Brown said softly. "But my doctor helps me cope. And that means the world to me."

Patients who have a continuing relationship with a personal physician, studies show, have greater survival rates and lower health costs. Conversely, the more medical personnel involved in the patient's care, the greater the likelihood of error.

But though that primary relationship is so fundamental for patients, the medical establishment is gradually turning away from it. The number of medical students eschewing careers in internal and family medicine and instead pursuing specialties is increasing. Among the reasons they give are the declining prestige of primary care doctors, the eroding doctor-patient relationship, the financial hardships of maintaining a practice and the drain on family life.

A study in the May issue of *Academic Medicine* showed that among third-year residents in 2003, 27 percent chose careers in primary care medicine rather than pursuing a

subspecialty, down from 54 percent in 1998. Only 19 percent of first-year students said they intended to be generalists.

"I can imagine patients feel lonely, 'My doctor didn't follow me,' " Dr. Russo said. "I wish I could. I wish I had the time to sit down with them."

Making the Decision

When Meg Gaines was a little girl, her father, a lawyer, was transferred to Belgium; the family arrived scarcely 20 years after the end of World War II. She grew up keenly aware of European history, visiting concentration camps and battlegrounds, learning about military strategies.

What was the best way to fight her war against cancer, she asked herself that night in 1995, as she struggled to decide about treatment. Stay the course with chemotherapy or risk the cryosurgery first, which, back then, was a relatively experimental and possibly lethal procedure?

"What made sense to me was to bring in the air force and bomb the hell out of the tumors and weaken them," Ms. Gaines said. "Then go in with the infantry. And so I decided to do surgery plus chemo, not just chemo."

As it happened, the Los Angeles surgeon found only one big tumor. The others, which had earlier scared off the liver surgeon in Wisconsin, were just blood density irregularities and benign cysts.

Eighteen months after Ms. Gaines's cancer was detected, she returned to her job, teaching criminal law and supervising students defending prisoners. The job was the same, but she had changed.

Over the next few years, Ms. Gaines did a lot of thinking and a lot of talking about her experience as a patient, about how brutally difficult it had been to gather information, find doctors and make decisions. She helped found the Center for Patient Partnerships, which opened in 2001, based at the law school of the University of Wisconsin-Madison. It helps patients with cancer and other serious illnesses find doctors and make informed decisions, even as it trains student volunteers from disciplines like law, business, public policy and medicine how to be advocates for patients.

"You can get good health care," Ms. Gaines said. "But there isn't good relay, getting you to the resources and the resources to you." She meets with panicky, bewildered patients and occasionally shares with them her story, if only to make one point: "I tell patients all

the time: 'I know this is hard to believe, but you want to know who is managing your health care? It's you or no one.' "