Why We Trust

We're cynics about insurance companies and critics of big health care syste

By Margot Sanger-Katz

Survivor: Mary Morse-Dwelley

Doctors

ms. So why do we still believe in physicians?

BANGOR, Maine—Mary Morse-Dwelley's abdomen tells the story of her medical travails. A long, straight scar crosses the top. Swirls of shiny pink skin dance across the middle, revealing the many unsuccessful attempts to close an incision—with synthetic mesh and Velcro, a vacuum-pack dressing, and ultimately a skin graft. A bulging hernia on the right side shows where her abdominal muscles atrophied after repeated infections and repair attempts. The bulge has grown in recent years without those muscles to protect her swelling organs from the vicissitudes of gravity.

Inside, it's not much better. Morse-Dwelley's belly, full of scars and adhesions, is missing her gall bladder, uterus, and more than two feet of intestines. There's a medical term for such an environment: a "hostile abdomen." It's the sort of place that most surgeons prefer to avoid.

"The question is, where am I going to start?" asks Dr. Joan Pellegrini as she surveys Morse-Dwelley's battle-scarred body in her office at Eastern Maine Medical Center here. She moves her hand up high, far above the hernia she hopes to repair. "I think I'm going to start here, in an area where there is no scar tissue." Morse-Dwelley, 60, points to a diagram of the digestive system that hangs above the exam table. "I don't have most of that," she jokes.

Her medical chart reads like an epic poem. Surgery to remove inflamed parts of her colon scraped away too much of her abdominal wall, which caused a strangulating hernia, which killed a section of her colon, which became infected, which induced septic shock, which required a series of unsuccessful repairs. She has undergone 22 abdominal operations, endured infections by antibiotic-resistant superbugs, spent more than 100 consecutive days in the hospital, and lived for nearly two years in bed. Through much of the ordeal, full of setbacks and complications, Pellegrini was her surgeon.

But Morse-Dwelley has been healthy for five years now. During that time, she watched her two children graduate from college, welcomed a grandchild into the world, nursed her husband through a heart attack, and helped his solo optometry practice recover from the missed days and medical bills that dragged them close to financial ruin. The crisis is over. For Morse-Dwelley, despite all the disasters, Pellegrini is the hero of her medical story. Today's checkup lays the groundwork for yet another operation next month.

This patient is no fool, and she doesn't award trust liberally. A vigorous labor arbitra-

tor, Morse-Dwelley has worked in tough political campaigns. Her brother is a priest, but she distrusts the Catholic Church. She says you'd have to be crazy to count on bankers, after the financial crisis. She saw how her long illness strained close relationships and taught her who her "real friends" are. Her husband's career has given her an up-close—and unflattering—view of how health insurers work. Her skepticism reflects broad social attitudes: Americans have grown more mistrustful of many professions—clergy, lawyers, politicians, journalists. *(See "In Nothing We Trust," p. 16.)*

Yet, somehow, Morse-Dwelley never lost faith in Pellegrini. She'd hear the click of her doctor's shoes in the hallway, see her blond hair and funky glasses, and feel confident that she was in good hands. This, too, represents a broad trend: As we have become better-informed patients, we have grown more cynical about a health care system that is ever more corporate and reliant on technology. Nevertheless, our faith in physicians has proved incredibly durable. Gallup, which has polled on public trust in professionals every year since 1976, reports high and rising marks for doctors. In the latest survey, from 2011, 70 percent of respondents rated medical doctors as high or very high when asked about their "honesty and ethical standards," a record. When the Kaiser Family Foundation asked Americans whom they trusted in 2009—the height of the debate over the health care law—78 percent said they believed that their doctors put patients' interests ahead of their own.

Amazingly, this trust persists even among people who have been harmed by their physicians, according to a growing body of research. As Morse-Dwelley suffered through repeated procedures, infections, and crises, she knew that Pellegrini didn't always make the perfect decision or get the best result. Many of Pellegrini's colon-repair surgeries failed. And Morse-Dwelley's belly rejected several artificial patches that the doctor inserted to compensate for lost tissue. At various points, Morse-Dwelley overheard other physicians advise Pellegrini to give up, saying that Morse-Dwelley was too sick to bear further rescue efforts.

Pellegrini pressed on, Morse-Dwelley believes, because the surgeon cared about saving her life. "A lot of the outcomes of the surgery were bad," Morse-Dwelley says. "But I had complete confidence that she was the only person there who was willing to keep trying." Intent, in the end, matters more than results. Now the two have been together for 10 years; they laugh like old friends.

How is that possible?

FORGED THROUGH FIRE

The collaboration took time to blossom. When Morse-Dwelley first met Pellegrini, she was in no position to bond. Septic, unconscious, and close to death, she needed emergency surgery to extract that gangrenous colon. Pellegrini, who had just moved to Maine to start her practice, got the call on Mother's Day.

So Morse-Dwelley's husband, Tom Dwelley, and her children (then a 14-year-old daughter and an 18-year-old son) had to size up the young trauma surgeon themselves. They were tough customers. Already, Morse-Dwelley had suffered mightily at the hands of doctors: A misdiagnosed gallbladder rupture had hospitalized her for weeks. An earlier colon surgery, which had failed to heal properly, induced raging infections. When daughter Carrie saw one surgeon whom she thought had mistreated her mother, the teenager began crying and screamed, "He's going to kill my mom." A nurse had to lead her away from the emergency room.

Pellegrini, however, telegraphed competence. Tom Dwelley remembers her as concerned, honest, and confident. And he put the health of his sick wife into her hands. "The moment she spoke to me, I had a feeling she knew what she was doing and she was going to help us," he says. The first surgery to repair Morse-Dwelley's compromised intestines began within the hour.

It failed. Pellegrini managed to remove the dead tissue, but escalating pressure in Morse-Dwelley's abdomen forced Pellegrini to reopen the wound. The next attempt didn't go much better. Or the third. Pellegrini's repeated repair efforts brought Morse-Dwelley back from sepsis and certain death, but the patient was still so sick that her body responded poorly to surgery. Pellegrini struggled to reattach the damaged intestines. Infections set in. When the first round of operations ended, Morse-Dwelley had an open 20-inch incision and a fistula—a hole in her bowel that made her prone to infection. She spent nine days in a coma and more than two weeks in intensive care. That was just the beginning of a months-long hospital stay.

It's difficult to know what made this case so complicated, Pellegrini says. Maybe she tried too many repairs too early. Maybe Morse-Dwelley's compromised immune system interfered with healing. Some cases simply defy expectations. Because the physician's job is to help the patient, and that proved so tricky, Pellegrini began to feel deeply invested. She was practicing alone, and she remembers visiting Morse-Dwelley in Room 319 every day for weeks, sometimes twice a day. She asked her children to pray for her patient. "You make a vow to the patient," Pellegrini

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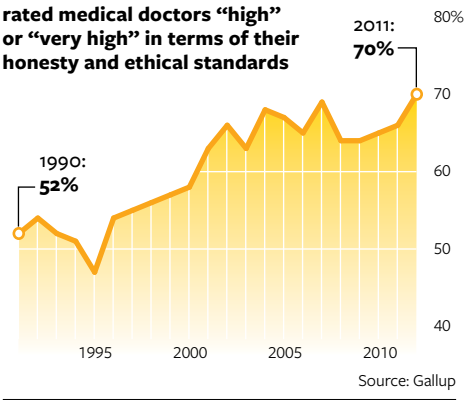
Rising Marks for Doctors

Despite cynicism about the overall health care system, Americans' faith in medical doctors has risen to a new high.



Source: Gallup

If at first ... Dr. Joan Pellegrini

says. "I am going to get you through this."

Morse-Dwelley explains that the personal bond ultimately mattered more to her than anything medical, and she ignored family members who told her she should transfer to Boston. "It wasn't a blind faith at all," she says of her loyalty in the face of adversity. "It was a faith in her really emotionally connecting with us. We knew that she wanted me to be alive as badly as anybody else, and she wasn't afraid to ruin her own surgical stats to help us."

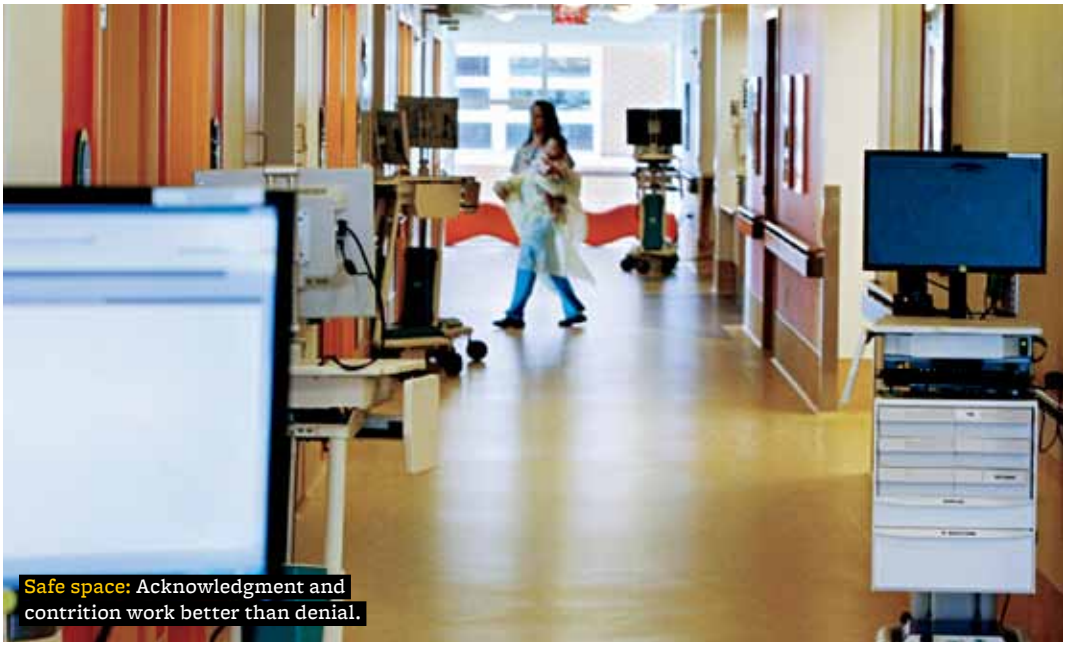
WHAT DOCTORS KNOW

At its core, medicine is a personal business. Even as health care has become more technological (surgical robots, electronic medical records) and physicians have become more squeezed for time, nearly every medical encounter involves a face-to-face interaction between a doctor and a patient. A machine may take your blood pressure, but a person still asks what ails you and then helps fix it. Pollsters and scholars of medical ethics say that this personal interaction is a key to doctor-patient trust.

When you ask patients if they trust doctors, they imagine their own doctors—specific people who have helped them when they were sick. A doctor is rarely seen as the agent of a big institution or, like a member of Congress, as a well-liked but distant individual. Your doctor is the person who sits in a room with you and helps to solve your problems. If you ask people how they feel about the medical system, they grade it much lower than they do physicians. "Trust in doctors is very much interpersonal trust," says Mark Hall, a professor of law and public health at Wake Forest University, who has studied the dimensions of the doctor-patient relationship.

Doctors benefit from a reputation for altruism that has remained mostly unblemished. They still take the ancient Greek Hippocratic oath, and most patients still believe that a desire to help, and not to make a profit, motivates their doctor. The medical profession has closely policed its ethical boundaries to preserve its standards.

The structure of medicine may also account for some of the lingering trust. The insurance system places an intermediary between care and payment, which makes it harder for patients to see doctors as profiteers. (Doctors who have their own imaging equipment have been shown to order more MRIs, for instance, but patients don't necessarily associate their physicians with the bills



Safe space: Acknowledgment and contrition work better than denial.

PHOTO: ASSOCIATED PRESS/KEITH SRAKOCIC

or realize that the additional procedures may be unwarranted.) "They believe the goal of the physician is for you to do better with your hypertension. It isn't to make a million dollars in selling hypertension medicine," says Robert Blendon, a professor at the Harvard School of Public Health who studies public attitudes.

Medical professionals haven't just relied on long-standing respect; they have also evolved with the times. In the past generation, the practice of medicine has undergone a sea change—from the old-school approach in which the doctor knew everything, made decisions, and told the patient little, to a new model that emphasizes patient understanding and choice. Medical schools added compulsory courses on communication and ethics, and the medical-licensing exam now includes an entire segment on doctor-patient interaction.

As patients began to question their doctors, doctors responded by welcoming that back-and-forth. They are more likely than before to explain the downsides of a treatment, share the honest odds of success, and honor a patient's choice that might differ from their own. "The medical profession has absorbed some of those influences, because patients are, in fact, better informed," says Dr. Albert Wu, a professor and the director of the Center for Health Services and Outcomes Research at Johns Hopkins Bloomberg School of Public Health. "The Internet and other sources of information are resulting in the need to team up more with patients."

For Morse-Dwelley, Pellegrini's honesty about the limits of her medical knowledge didn't weaken her stature; it enhanced it. Pellegrini professed confidence but admitted that she was new and that she hadn't specialized in intestinal repair. When Morse-Dwelley's fistula persisted after multiple operations, Pellegrini called gastrointestinal surgeons for advice and attended every session about fistula repair at a national conference. She read up on new wound-closure techniques. She told the family that Morse-Dwelley's chance of surviving a particular bowel-repair procedure was only 5 percent. "To me, nobody knows all the answers," Morse-Dwelley says. "Anyone who's willing and secure enough to be out asking for input—what have you heard?—[that] inspired me to no end. If she'd come across like some surgeons, like, 'I know best,' I would have left."

Doctors and liability insurers are slowly learning this lesson. The traditional response to medical error was for a doctor to admit nothing and make it as hard as possible for patients to sue. But new research shows that even in situations where mistakes (not just bad luck) have harmed patients, it's possible to preserve trust. Patients, it turns out, frequently accept a provider's honest apology. "I've seen that over and over again," says Dr. Steve Kraman, a professor of pulmonary critical care and sleep medicine at the University of Kentucky College of Medicine.

As the chief of staff at the Lexington Veterans Affairs Medical Center in the 1990s, Kraman implemented a policy of disclosure and apology any time something went wrong. It was his job to personally deliver the bad news to patients who had been harmed by poor care. The results—lower liability costs and less bad will—led the VA to implement the policy nationwide. It is now (slowly) becoming the standard of care in medicine. "It is, at its foundation, a human relationship, and the patient wants very much to trust their doctor," Kraman says. It's also a lesson that politicians, and others who err on the job, could stand to learn: People forgive honest mistakes but not denials and cover-ups.

Unlike choosing a car (which has a crash-test rating) or retaining a lawyer (who has a win rate), picking a medical practitioner is not really a fact-based process. It's hard to find a meaningful metric that shows whether a doctor is great or mediocre. Although advocates and policymakers are trying to improve measures of quality and patient access to ratings, most patients still make decisions blind. "How does a patient know anything about me?" asks Pellegrini, wondering how she would select a surgeon if she got sick. "Maybe I'm just a personable doctor, and my outcomes suck," she says.

And here's the crazy part: Despite the leap of faith required to trust a doctor, data show that patients who do so have better health care outcomes. Studies find that patients with the most trust are likelier to take their medications, engage in healthy behaviors such as quitting smoking, and return for follow-up care. Medicine may be one of the only markets where a skeptical consumer is likely to end up with a worse product.

FACING IT TOGETHER

As Morse-Dwelley prepares for her next surgery, she's trying to think of everything. She'll bring signs to remind the staff in her wing that she's allergic to betadine, a common antiseptic, and the adhesive in medical tape. ("Don't screw with me! Read that sign, because otherwise my skin falls out.") She made sure that her medical record notes the bad reaction she had to an older anesthesia drug. She has updated her advanced directive so it says, in effect, "Do everything to save me."

She asks Pellegrini about scary, antibiotic-resistant bacteria she has read about. She has already had a dangerous infection known as MRSA, but what about another sometimes fatal one known as C.diff? She asks about the surgical materials Pellegrini might use, reminding the doctor that her body has rejected others, leading to more surgery.

But, in the end, she knows that if she's going to go through with it, she'll have to give up control and trust Pellegrini to take care of her. "It's a big step," Pellegrini says somberly.

"We'll get drugs for the family," Morse-Dwelley jokes. She knows they're skittish, too.

Then they laugh, and talk about the kids, and hug good-bye. ■

This story is part of a yearlong series that examines America's crumbling foundations and how to rebuild them. Find more on the Web at nationaljournal.com/restoration-calls.