Under My Skin

The Invisible Exit Sign

On the wooden door that leads from my examining room corridor out to the waiting room, a big red sign at eye level reads EXIT. This sign is invisible. Time and again, patients trying to leave walk up to the door, stare at the sign, then turn left, until somebody rescues them and shows them out.

BY ALAN ROCKOFF, M.D.

The trouble actually starts sooner. When patients exit the exam room itself, another red sign directly opposite, also at eye level, reads EXIT, with an arrow pointing to the right. This, too, is invisible. At least half of the patients turn left and soon bump into a blank wall, on which I have placed a sign reading, THE WAY OUT IS BEHIND YOU. They ponder this sign—and the blank wall behind it. After a short pause for processing, the message gets through and they turn around.

Few of my patients are blind or illiterate, so why are my signs invisible? The reason is their unfamiliar context. When you don't know where you are, you can hardly see anything. To process data, our senses need the help of background cues.

How much this matters becomes obvious on trips abroad. When people speak to us in a strange language, for instance, we often can't even pick up words we know. Mumbling happens everywhere, but back home we can understand it because we get the rest of the sentence, know what facial expressions and gestures mean, and so forth.

Patients in our offices are travelers in strange lands. We are so at home that it takes effort to realize how lost the patients can get in matters of procedure and etiquette, not to mention medical advice.

Perhaps we and our staffs should think of ourselves as folks who greet tourists at a Visitors Bureau in a country where the people talk funny, act weird, and drive on the wrong side of the road. Here are a few tips:

► **Checking in.** People who are not experienced in HMO-land can be pardoned for assuming that if they call their primary care physician and he or she promises to send a referral, then the doctor has done the job. We know better, of course, but it's fair to be gentle rather than huffy with patients whose referrals have not yet been sent in.

► **Taking a seat.** In each of my exam rooms, in addition to the table, I have a stool and a chair. I sometimes enter to find a patient leaping to her feet and stammering, "Sorry, I'm in your chair!" It helps if the staff member who bring patients into the room tells them where to sit and shows them where to hang clothes. (Door hooks also are invisible.)

► **Putting on a gown.** That you should leave a gown open in back is not self-evident, especially if you're worried about your front. Proper gowning takes both instruction and demonstration. (Even that may not be enough. At my most recent colonoscopy, they told me to put on two johnnies, an upper and a lower—and showed me, too—but I still got them wrong. Both of them.)

► **Lying down.** As everyone knows, if you tell a patient to lie on his back, he will lie on his stomach. If you ask him to lie on his left side, he will turn right.

► **Knowing what we do for a living.** Just because we know what diagnoses we handle and which procedures we perform doesn't mean that our patients know. They ask me things like, "Do you take care of warts?" Even more often, they apologize because their rash got better or their bleeding spot fell off before they came, assuming that anything less than cancer or complete misery is a waste of my time. It doesn't take much effort to assure them otherwise, or to unintentionally embarrass them by acting bored and dismissive.

► **Going for samples.** Unless I tell them emphatically to stay put and that I will be right back, patients who see me leave to get samples are often overcome by fear of abandonment and come running half-clothed into the hall.

► **Understanding instructions.** When do you put the cream on? Must you wait after washing? Do you leave it on, or wash it off? And so on and so forth. Many of these directives, self-evident to us, are anything but that to our visitors.

► **Exiting.** You already know about that.

The bottom line is that when you don't know where you are, almost anything, no matter how simple and obvious, can be inscrutable. Or invisible. ■

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Pro & Con

Should patients be required to take part in comparative clinical trials?

YES

Although some studies raise the concern of whether patients are put at too much risk, we must also ask if research safeguards are sometimes overly protective of people who might enter clinical trials.

As I wrote in the September-October Hastings Center Report, there are many medical problems for which physicians can choose among multiple therapeutic options, and the decision is typically based more on hunch than on data. Patients would benefit greatly from studies that clarify the benefits and risks of different options for their illnesses.

But these studies are delayed—and medical progress impeded—by difficulties in securing the participation of enough individuals. In one study comparing the two leading therapies for chronic atrial fibrillation, only 55% of patients invited to enroll agreed to do so.

Given the difficulties in enrolling patients, physicians should be able to make access to treatment they provide contingent on the patient's willingness to enter a clinical trial, when the trial compares two or more accepted therapies to determine if one is superior.

Patients would not be subjected to any risk by their participation—they would be receiving treatment that, under current knowledge, is as good as the alternatives—and they would be free to decline participation and receive care from another physician. Of course, patients should not be required to take part in trials of experimental therapies; such a requirement would be unethical.

Some people are concerned that making treatment dependent on clinical-trial participation would undermine the patient's trust in the physician. Although this concern is important, it shouldn't lead us to reject the idea entirely. Past abuses of clinical trials have involved either lack of informed consent or an unacceptable risk to patient health, neither of which we are talking about here. Conducting clinical trials might actually bolster patients' trust in their physicians by assuring them that their doctors are trying to find out which treatments work best.

Some people may also worry that patients will feel pressured to enroll in the study. But if they agree to participate, they will not be placed at any greater risk than if they decline. They can always decline participation and receive their preferred care from another physician. Moreover, the purpose of the pressure is to encourage patients to help doctors understand and treat disease. There is nothing wrong with reasonable efforts at persuasion that will foster socially desirable behavior. ■

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NO

As a physician who has conducted clinical trials, I've found that the most important thing in getting patients to participate in a study is to be able to offer the patient a choice.

When there is a trial that involves two therapeutic regimens, the patient should have to give informed consent and should be given latitude not to participate without sacrificing the physician-patient relationship.

Although it can be challenging to enroll patients in a study, we should respect the fact that patients are masters of their own destinies. That may be looked on as stonewalling the progress of medical science, but we serve our patients one on one and build our relationships on trust.

If the patient is given a choice of Plan A or "I'll no longer be your physician," then it would further the science of medicine, but it also would detract from the healing process.

An integral part of healing is not only the medicine we give, but also the trust patients afford us and the relationship that patients have with their physicians.

The way I look at it is, how would I want my family—or even myself—to be approached or treated? I would want family members to have the ability to make a decision.

Although the research and data express a sense of urgency about being able to further medical science, we can't lose the importance of patients whom we serve in the name of medical science.

My own experience as a researcher in a comparative study of two hypertension drugs has been that when patients are given proper informed consent about participating in a study, we can get a 90% or better participation rate.

If you have a study that you think one of your patients might benefit from, you can say to him, "There are two arms of this study, Arm A and Arm B. And looking at your problem list, you seem to meet all the criteria for the study, and you might benefit from it—with free medical visits and free medication—and you'll also be helping people."

When you present that to patients, few will be averse to it.

This is an anecdotal result, but I didn't think I needed at any time to strong-arm anyone into participating. The patients took advantage of the free office visits and free medicine, and no one gave them an ultimatum.

As long as patients are educated and well-informed, they recognize the benefits of participating in studies. ■

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