

# Science-Based Medicine

Exploring issues & controversies in science & medicine

## When impressive science fails to impress patients

By David Gorski on March 24, 2008

One of the greatest challenges in medicine can sometimes be to convince patients that the results of scientific and medical research apply to them, or, at the very least, to explain how such results apply. One of the reasons that medicine based not on science or evidence flourishes is because it can be so hard to explain to patients why a particular intervention is viewed as effective. My co-blogger Steve Novella wrote about some of the fallibilities of human perception that lead to perceiving correlations and treatment effectiveness where there are none. R. Robert Bausell wrote about the same thing in his recent book *Snake Oil Science*. While it is undoubtedly true that people tend to pay more attention to anecdotes than to studies and statistics, there is also another reason why doctors often have problems convincing patients of the value of health interventions, and that's the difference in perception and how we value different kinds of evidence.

A couple of years ago, I came across an article that explains this gulf between how those of us trying to practice science- and evidence-based medicine perceive the world and how most human beings not trained in medicine or science perceive it. The article, which was published in 2006 in the *New York Times* and written by Dr. Abigail Zuker, proposed one reason why this might be, beginning with a discussion with her mother in which she tries to convince her of the benefit of exercise, even in the elderly, a concept that her mother would have none of and dismissed contemptuously:

“Studies,” she says, dripping scorn. “Don’t give me studies. Look at Tee. Look at all the exercise she did. She never stopped exercising. Look what happened to her.”

End of discussion. Tee, her old friend and contemporary, took physical fitness seriously, and wound up bedbound in a nursing home, felled by osteoporosis and strokes, while my mother, who has not broken a sweat in the last 60 years, still totters around on ever-thinning pins. So much for exercise. So much for studies. So much for modern clinical medicine, based on the randomized allocation of treatment and placebo. All that beautiful science, stymied by the single, incontrovertible, inescapable image of Tee, the one who exercised but grew hunched and crippled anyway.

My first thought would be that such a reaction represents the power of anecdote over clinical data, but Dr. Zuker sees more than that. She sees it as the difference between how doctors are trained to view the world and how people untrained in medicine and science view the world, and she uses a rather interesting metaphor to convey this difference:

It is medicine’s eternal quest, these days, to sell impressive science to unimpressed patients, and it is hard to think of a group less equipped to do it than doctors. Doctors are specifically trained not to think like normal people, not to see what others see or to reason as others reason. They — er, we — come to operate in an atmosphere so thin, so heady and attenuated with the power of statistical analysis, that one might wonder whether we are really on the same planet as the patients we try to convince of our truths.

“Exercise helps the elderly.” The doctor sees, from a perch suspended somewhere up in the sky, a large football field filled with the elderly. There are thousands of them down there, all dressed in sweats and sneakers, dumbbells at their feet. Half of them are using the dumbbells, or are down on their backs, doing leg lifts. The others just stand around.

Over the years, of course, the ranks thin. The doctor watches, counts. It begins to look as if there are more exercisers left. After decades, there are definitely more exercisers. Of course, there are still a few sloths standing around (and one of them looks suspiciously like my mother). But by and large, the exercisers come to rule the field.

That is the view from on high. Down on the field, of course, the view is quite different. You are standing in a thick crowd, minding your own business, living your life, but you cannot help noting that the man over there threw his back out with all that exercise, and the woman next to you, grunting to lift her dumbbell, had a heart attack. You cannot see to the other end of the field and have no idea what is happening there. But watching all the sweating and grunting and seeing some of those exercisers disappear anyway, you decide to opt out.

This is one of the best metaphors for the gulf between how we as practitioners of science-based medicine and patients see clinical and epidemiological research that I've ever come across. The aspect of clinical research that is hard to explain to patients is that interpreting the results of clinical studies and applying them to patients is entirely a matter of probabilities. From clinical studies, you can conclude that exercise will increase a person's chance of living to a ripe old age. However, some people, either through good genes or sheer luck, manage to make their way through life without exercising and live to a ripe old age anyway. (Think George Burns, who lived to 100 despite a love of cigars and booze.) Similarly, we can say that, by and large, smoking can greatly increase your risk of heart disease, lung cancer, and premature death. But, then, everyone knows someone who smoked for 70 years and died at age 85 of old age, apparently suffering few ill effects from the thousands upon thousands of cigarettes he smoked. Indeed, heavy smokers have "only" approximately a 25% lifetime risk of developing lung cancer. That leaves lots of smokers out there who never develop lung cancer and makes it easy for some to ignore the fact that heavy smoking increases one's risk of developing lung cancer by a huge amount and that lung cancer was considered a rare disease before the advent of cheap mass-produced cigarettes. Now it's consistently in the top two or three causes of cancer death, and that appears to be entirely due to tobacco use.

It's sometimes very hard to overcome the power of anecdote and patient experience, even for such clear-cut cases. For example, take the rather common discussion of the pros and cons of breast conserving therapy (lumpectomy) versus mastectomy for breast cancer. Every surgeon who does breast surgery will get the occasional patient who demands a mastectomy for a small tumor that would be most appropriately treated with lumpectomy. In my experience, the reason almost always boils down to a bad personal experience. Often such patients had a close relative or friend who had breast cancer treated with lumpectomy and recurred. Often, if you probe a little more closely, they will tell you the horrific tale of how the cancer ravaged a loved one after it recurred. They become convinced that it was because the deceased hadn't undergone the more radical treatment of mastectomy that her cancer killed her. No amount of citing the three decades of large studies demonstrating that five and ten year survival are the same for lumpectomy and radiation therapy as they are for mastectomy will sway them. The patient doesn't care; she wants a mastectomy. This is even more true when you inform her that there is around an 8% chance of local recurrence with lumpectomy but that it doesn't affect the overall survival rate. All she hears is that there is nearly a one in ten chance of the cancer coming back in her breast after a lumpectomy but a less than 1% chance of its doing so after a mastectomy. Statistics tell the doctor that her chances of long-term survival will be the same with a lumpectomy as with a mastectomy. The patient's experience tells her otherwise. Therefore, she insists on a mastectomy, and, because it is a perfectly acceptable treatment for breast cancer and because she has the right to control what happens to her body, she usually gets it, even though usually more than one surgeon try to talk her out of it and even though she could surely have been treated for her cancer without losing her breast. This same phenomenon seems to be progressing, at least from my—forgive me—anecdotal experience. Women with small cancers seem to be requesting more and more to have both of their breasts removed, even though such a prophylactic measure can be justified scientifically primarily in women with a genetic mutation or a family history that puts them at a very high risk of breast cancer and such operations are not without a cost in complications and decreased quality of life. Such a trend away from less radical surgery towards even more radical surgery is also being fed by us physicians as well in the form of ever more sensitive imaging modalities like MRI that find ever smaller cancers that may never develop into life-threatening disease or find small pockets of disease that normally wouldn't have been detected before and would have been "mopped up" with post-lumpectomy radiation therapy.

It is this gulf in perception that will lead some patients to refuse chemotherapy even when there is clear-cut evidence of a significant survival benefit or sometimes even in the case when it is the only curative treatment available. When this occurs, it is often because the patient either knew someone who underwent chemotherapy and died anyway, even if the cancer was a high mortality cancer that chemotherapy had a small chance of curing, or someone who had a complication from chemotherapy, such as neutropenic enterocolitis, and died from the complication rather than the tumor. From their "ground level" perspective, they don't see that the number of surviving patients with this particular cancer at this particular stage who receive chemotherapy is far larger than the number of those who don't receive chemotherapy. They may not even realize that in the case of some tumors (leukemias and lymphomas, for instance), virtually no one who is not treated survives his or her cancer. All they see is that someone they knew had chemotherapy and died from it. Indeed,

various “alternative medicine” sites do their best to feed this perception by emphasizing the complications of chemotherapy, using terms such as “poisoning” and “burning” and making incorrect claims that chemotherapy harms more patients than it helps.

If the power of anecdote can be difficult to overcome in such clear-cut cases, imagine how hard it can be to do in cases where the decisions are not so clear cut or where the treatment proposed offers only a small benefit. One such example is whether or not to use adjuvant chemotherapy after the treatment of various cancers, where, depending upon the cancer and the stage, the increase in absolute chances of survival can range from as little as 3% to as much 20-25%, but rarely more. In the case of stage I breast cancer, for example, the absolute survival benefit due to adjuvant chemotherapy is on the order of 3%. Even so, most patients will still opt for even this modest benefit. Consider next the case where the literature and studies are either lacking, of poor quality, or multiple and in conflict, and you can see why patients, not to mention physicians, will base their decision more on personal experience than science. All of these are barriers to practicing science-based medicine.

Dr. Zuker suggests some strategies to persuade the patient:

Good doctors learn some tricks, over the years, to let patients see what they see. It helps, sometimes, to descend part of the way down from the sky and give a smaller version of the big picture. (“Of all my patients, it’s the ones who exercise who do the best.”) Sometimes it helps to get down completely, and see what the patient sees (“Your grandmother smoked till she was 90, but you may not be so lucky.”)

But sometimes there is no convergence of views. The patient who sees only from the ground, the doctor who sees only from the sky may simply have to agree to disagree, and have the same dialogue over and over again.

Another way we in medicine can overcome this gap, it is suggested, is to develop tests that help us predict far better than we can which patients will respond to which drugs and which patients are at higher risk for various complications. This “personalized medicine,” based on genomics and other factors, is at present a hot area of research, but I’m not entirely convinced that it will narrow gulf between patient and physician perceptions that much, because even if these tests can produce more precise information upon which to base treatment choices, it will still come down to a matter of probabilities. It will still come down to a matter of the gulf between the perception of physicians looking at the stadium from the air and the patients at ground level. The only difference will be that we’ll be saying “patients with this genomic profile” are more likely to respond to a treatment than those without. I’m not sure that will help bridge the gap that much.

Of course, I would point out to Dr. Zuker that it is not only patients who can fail to see the forest for the trees. Doctors often fall into this trap as well. If, for example, we see a treatment resulting in a bad outcome in two patients in a row, we are just as prone as anyone to react by changing our approach, even when the scientific literature tells us that we are using the most efficacious treatment available and that the last couple of bad outcomes were almost certainly a statistical fluke.

At the clinic level, dealing with real patients and real complications, we physicians often can’t see the “whole picture” either, and that is one reason why it is so important for us to stay current on the medical literature and to be willing to reach out to their colleagues for advice. In my experience, surgeons tend to be particularly prone to this “last disaster” sort of thinking. Sometimes this is a good thing, as in when a string of wound infections leads one to wonder if one’s sterile technique is not what it should be, but it can also lead to major changes in treatment choice based on anecdotes.

In the end, bridging this gap in perception is largely a matter of communication. This is one subject for which doctors are generally not well trained, either in medical school or residency, and one area that I wish I had become better at. In a sense, even now, I am still learning and still trying to improve. However, as Dr. Zuker points out, often that isn’t enough, and, as I like to point out, it is this gulf that makes it all too easy for practitioners of dubious unscientific medicine to persuade patients that their unproven or ineffective nostrums are superior to science-based medicine.