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## When the doctor is crazier than the patient

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**L**IKE THE CHILDREN IN Lake Wobegon, all doctors think, I believe, that they are above average. Or, at least average. Yet we are not. Some are sub-average because they are out of date and either cannot or will not keep up. Some were never too bright or well educated in the first place. Some are lazy. Some are overconfident and fail to challenge themselves. Others age poorly, especially in the technical areas of medicine. But there is a small group of us who practice poor medicine because they KNOW things that the rest of us fail to grasp. There is a doctor who sells an intravenous protein that he believes, or says he believes, stops Parkinson's disease from progressing. While its use has a theoretical rationale, it has never shown promise and his only returning patients are the "true believers," who either have had placebo benefit or, more likely, choose to believe that they are not worsening, despite evidence to the contrary. I attended a meeting of invited Parkinson's disease experts to discuss particular issues related to the disease. One of these experts, someone with a fine reputation, opined on how wonderful a particular dementia drug worked in PD patients, an experience neither supported by data or by anyone else's experience. As one colleague suggested, "I



guess we should send our demented patients to you since that drug doesn't work too well where I practice." Another expert waxed eloquent about how an experimental drug in a double-blind placebo-controlled study was astoundingly helpful. The doctor and the patients all "knew" they

were on active drug. Another researcher, who saw all the patients for an imaging piece of the study, but was not treating any of them, noted that all the subjects reported how much improved they were, although half were on placebo. The drug was, in fact, useless.

We all "know" things. We're all influenced by our experience, particularly the last two or three cases, but most of us recognize this. We can distinguish between what I call "experience-based medicine" and "evidence-based medicine." Early in my career I had access to a drug that was experimental but was able to use on an open label compassionate basis. In my hands it was a miracle drug. So, after many years I was able to get funding to study it in a double-blind placebo-controlled manner. As the study was ending I became distraught because I could not tell which patients got the active drug and which the placebo. I was prepared to be devastated by the results, which, in fact, showed that the drug was

near miraculous, later confirmed with a repeat study in Europe. Yet another drug which I thought almost as good produced negative results in three separate similar trials. Blinding is the best approach.

There are doctors who believe their experience over that of well conducted trials as well as expert consensus panels. And these beliefs are supported by a small percentage of patients who reject modern science in favor of beliefs that make sense to them. The largest groups I'm familiar with are the believers in autism being caused by vaccinations, the Lyme-explains-everything group, and the food "allergies" patients who believe that their illnesses have to do with eating something they are uniquely unable to process. The current food problem is gluten, but that will pass soon and be replaced by other things. The autism belief is, of course, not fading despite the bottom having fallen out of the supportive "data." The Lyme belief has been persistent, possibly now expanding to include all tick bites as potentially causative of many disorders, whether there is evidence of an infection or not, whether it was treated or not.

We cannot control what our patients believe, and patients sometimes have their own ideas of what their diagnoses should be. In Rhode Island this tends to be Lyme disease, which can apparently take on more guises than the previous "great imitator," tertiary syphilis. I have

seen significant numbers of patients who are loath to believe they have Parkinson's disease, tics, or some other disorder, including the psychogenic, when Lyme disease would be a much easier and more acceptable diagnosis. The preferred diagnosis would also not likely be progressive, and, although it had not improved with three month's worth of antibiotics, would likely be cured in the future with newer antibiotics. It is much more appealing, and easy to blame a problem on a nasty tick. And tick bites are not genetic. Or it may be due to gluten. Watch what you eat, suffer a bit, and you will be rewarded.

I learned from a multiple sclerosis expert at the University of Massachusetts that many of his patients had been treated for brain Lyme disease for months or years before they found their way to the MS clinic where the

diagnosis was readily apparent. I'm sure Lyme is invoked in all areas of medicine, depending on location.

I understand why patients would like to believe these things. It makes sense to find an explanation for an illness. Why am I slow and have tremors? Lyme disease is a more comforting answer than Parkinson's disease, whose etiology remains unknown. Lyme comes from a tick bite, an unpleasant way to get an unpleasant illness, but understandable. Wrong place at the wrong time. Bell's palsy used to be caused by exposure to cold air on one side of the face, as from staying in front of an air conditioner for too long. Acne was caused by chocolate and oily foods. Gastric ulcers were caused by spicy food. Humans like rational explanations, even when incorrect.

What is puzzling is why some doctors make a career of it. ❖

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## Addressing patient biases toward physicians

HERBERT RAKATANSKY, MD

**R**ACIAL INEQUITIES IN THE delivery of health care to minority populations are well documented. Less discussed, but equally important, are patients who exhibit racial bias and refuse care from health care workers (HCWs) because of their ethnic and/or religious backgrounds.



Their requests for accommodation can adversely affect their care as well as the care of other patients in the institution.

As much as doctors might dislike or condemn a person (ex: a terrorist), we strive to separate our dedication to healing from our personal opinions about the patient. Even the NY terrorist who recently killed 8 people and injured many others by driving a truck into them was taken to a hospital and treated. In war we treat the wounded enemy.

We are forbidden by ethical and legal imperatives to discriminate against patients on the basis of virtually any criteria except our medical expertise in treating the disease and, in non-urgent situations, the ability of the patient to pay.

Patients, however, are free to choose their doctor and to use any criteria they please, including Internet surveys, personal recommendations, race, religion, gender and age, among others. This process works well in the traditional out patient office setting. But what happens when a patient comes to an

ER, urgent care center or hospital? Does the patient retain the right to those choices?

There are some cases where the patient's request may have medical justification. For example, a woman with PTSD from previous sexual trauma might be more effectively treated by a

female physician. In some religions, women have no contact with men outside their families and treatment by a female physician might be more effective.

But what about refusal by patients, based solely on bias and bigotry, to allow certain HCWs to treat them?

One Muslim ER resident was told by two patients that they did not want to be "taken care of by a terrorist." In another case a senior ICU physician was told, "Go back to India. I don't want to see you." In one study 9% of Muslim physicians had a patient refuse care from them. 59% of doctors experienced bias from patients. "47% of 822 doctors surveyed had a patient request a different clinician because of that provider's personal characteristics."

Even doctors, when they become patients, may feel some bias. A black, woman anesthesiologist stated, "I immediately feel more at ease with clinicians sharing my cultural background." But she also concludes, "I would never refuse a health care

professional because of his or her demographic characteristics."

In one reported case the parents of a child consented to heart surgery only if no black people were allowed in the OR. The team acceded to this request.

We might expect that hospitals and health care systems would have policies about how to respond to these requests. 24% of physicians said their institutions lacked a formal process. HCA has no system-wide policy. AAMC has no "formal, specific guidelines." The AHA is "developing a best practice resource guide based on policies hospitals are already using." The largest RI health care system does not have a specific policy or procedure but currently is working on this issue.

If the HCW is an employee of the institution, acceding to a patient's request to not be cared for by a person because of race, religion, etc. may be illegal. The Seventh Circuit Court of Appeals has ruled that Title VII prohibits such discrimination in the workplace. Many doctors, however, as members of the medical staff and independent contractors, are not employees of the institution and therefore are not covered by Title VII.

Most patient requests of this nature are quietly resolved and not reported to the institution. Physicians "may be afraid of being ignored or accused of being overly sensitive."

Doctors who have been in this situation often feel depressed and their

self-worth is questioned. This may contribute to burnout (over 50% of physicians have symptoms of burnout). Hospitals should be sure that such biased requests are dealt with openly and not hidden. These instances of bias impact the health of our professional caregivers and thus decrease effective care for all patients. Increased burnout results in decreased productivity, early retirement and job switching.

The institutional financial consequences are significant. Lower productivity means less revenue. And it is estimated that the total “organizational cost” to replace one full-time doctor is \$500,000–\$1,000,000.

Larger institutions will be able to deal with these issues more easily. It is especially important for academic training centers to be aware of this issue and have structured responses to these requests. Trainees must understand the psychodynamics and the ethical principles involved.

In the final analysis doctors must always act in their patients’ best interests. And that may involve giving in to patient bias in certain circumstances. A step-wise process to protect patients while upholding our values might resemble the following.

First, the patient should be counseled

about the qualifications and skills of the HCW and told that the institution rejects racism and bigotry at all levels. Hopefully this will result in acceptance of the assigned HCW. In the event that such interventions fail, a consistent approach should follow.

If the request is determined to be medically appropriate (see above), accommodation would be considered to be a part of the care plan.

If the request is driven by bias and prejudice, a progressive process that protects all patients and supports our opposition to racial and other invidious inequities should be in place and followed.

In emergency situations: if alternative HCWs are available and if other patients would not be harmed by the re-arrangement of the schedules such requests should be accommodated.

In non-emergency but urgent situations the patient should be offered an opportunity to transfer to another institution that would accommodate the patient’s requests. If no such treatment facility is available and the patient would suffer significant harm without treatment, the request should be accommodated if possible (other HCWs available and other patients not put at risk).

In both of these situations, if it is not

possible to accommodate the request, the choice of whether to be treated by the original assigned HCW resides with the patient. Treating a patient without consent violates our ethical and legal obligations. Unwanted treatment could be considered battery, a criminal offense. Adult capacitated patients have the right to refuse medical care for any reason, even if serious harm or death might result.

In medical situations in which there is no imminent danger of patient harm, the HCW or institution may, and I believe should, deny requests that are based solely on bias and bigotry. Why would a health care institution wish to do otherwise?

The combination of ethical and moral issues, personal distress of HCWs, quality of patient care and institutional financial risk should be sufficient to stimulate health care institutions and associations to formalize specific policies and guidelines that will enable and empower the staff to deal promptly and effectively with this difficult subject. ❖

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