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***The Life You Save:
Nine Steps to
Finding the Best
Medical Care -- and
Avoiding the Worst***

What to Do When the Doctor Doesn't Know What's Wrong

Physicians are only human. Yes, it's true. And as humans, doctors don't always have all the answers their patients seek. What do we patients do about that?

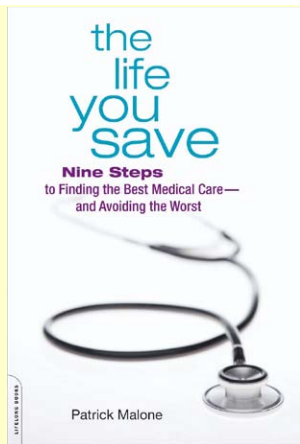
This month, we excerpt and interpret a thoughtful essay by a doctor who grapples with his inability to figure out each problem for every patient. It's an important essay that helps us patients better understand the doctor's perspective, and better communicate our own fears and uncertainties. And that helps us all become better patients and happier humans.

The essay, "[When Doctors Don't Know What's Wrong](#)," was written by Alex Lickerman. It appeared on his blog, "Happiness in this World: Reflections of a Buddhist Physician." Lickerman, assistant vice president for Student Health and Counseling Services at the University of Chicago, writes the blog to explore health and happiness from a scientific point of view and to help people think about important things in new ways. He touches people deeply -- comments continue to be posted long after he wrote the essay, and I've included a few here. [I contributed my own thoughts](#) not long after Lickerman posted.

There's Science, and There's Bias

When he can't figure out what's wrong with a patient, Lickerman starts with science.

"Believing a wacky idea isn't wacky in and of itself," Lickerman wrote. "Believing a wacky idea *without proof*, however, most certainly is. Likewise, disbelieving sensible ideas without disproving them *when they're disprovable* is wacky as well. Unfortunately, patients are often guilty of the first thought error ('My diarrhea is caused by a brain tumor') and doctors of the second ('brain tumors don't cause diarrhea, so you can't have a brain tumor'), leading in both instances to contentious doctor-patient relationships, missed diagnoses and unnecessary suffering."



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That conflict might prompt some doctors not to order tests a patient wants if he or she is perceived as wacky. If they do run tests that turn out to be negative, docs might suggest that the patient's symptoms are psychosomatic (that is, rooted more in a mental than physical problem). And if the symptoms persist, some doctors might refuse to pursue their cause.

"Sometimes," Lickerman observed, "these judgments are correct and sometimes they're not -- but the experience of being on the receiving end of them is always frustrating for patients. ... the best you can sensibly hope for are judgments based on sound scientific reasoning rather than unconscious bias. Unfortunately, though, even the minds of the most rational scientists are teeming with unconscious biases. So a more realistic strategy might be to attempt to *leverage your doctor's biases in your favor.*"

How Doctors Think

The best way to leverage bias is to know how doctors think. They're trained to consider a list of things that might cause symptoms a patient exhibits. They consider the entire list of everything known to cause the first symptom, then a second list of everything known to cause the second symptom, etc. This approach is called "novice" thinking.

Then they compare diagnoses that appear on all their lists to create another list, called the "differential diagnosis."

More experienced physicians use "expert" thinking, which relies on pattern recognition. This might be described as the art of medicine.

But if patterns don't emerge and a clear diagnosis remains elusive, a doctor might:

Revert to novice thinking. About 9 in 10 diagnoses are made from a patient's medical history, so if a doctor can't figure out what's wrong, he or she returns to the patient's story and digs deeper. That effort might suggest doing more tests, which some doctors might prescribe and some won't.

Ask a specialist for help. This requires the doctor to recognize his or her shortcomings. Some will, some won't.

Cram the symptoms into a diagnosis he or she does recognize, even if the fit is imperfect. This might seem misguided, but it often yields the correct answer. Lickerman

explained: "We have a saying in medicine: uncommon presentations of common diseases are more common than common presentations of uncommon diseases. In other words, presenting with a set of symptoms that are unusual or atypical for a particular disease doesn't rule out your having that disease, especially if that disease is common. Or as one of my medical school teachers put it: 'A patient's body frequently fails to read the textbook.'"

Deem the symptoms to be the result of stress, anxiety or some other emotional disturbance. This reflects the mind's power to manufacture physical symptoms from psychological disturbances. But a diagnosis of stress and anxiety should never be made by *exclusion*; that is, by ruling out every other reasonable possibility for symptoms, leaving only stress and anxiety. Such a determination is more substantial when it's made from *positive* evidence; that is, you feel stressed and anxious *about something*.

Doctors frequently invoke the psychosomatic explanation for a patient's symptoms when testing fails to indicate a physical explanation. That's sloppy thinking. "Just because science has produced more knowledge than any one person could ever master," Lickerman said, "we shouldn't allow ourselves to imagine we've exhausted the limits of all there is to know.... Just because your doctor doesn't know the physical reason your wrist started hurting today doesn't mean the pain is psychosomatic."

You might have an overuse injury (you've been walking all your life and suddenly your heel starts to hurt); your heart rate is faster, even at rest; your eyelid muscles start twitching; you have unexplained headaches.

Ignore or dismiss your symptoms. This is not the "time heals all wounds" approach that sometimes is appropriate. It's an unprofessional reaction to being confronted with a problem the doctor doesn't understand or know how to handle.

Bending the Bias Your Way

Getting the best care from your doctor means freeing her as much as possible from the influences of her biases. It means understanding the common things that happen to doctors.

They fall behind. A doctor might work slowly, or often spends extra time with patients who are especially ill or upset.

They have difficult or demanding patients. It's hard not to be defensive or paternalistic when there are too many tough customers.

They feel like they don't have enough time to do a good job. These days, doctors have fewer resources and more regulatory and bureaucratic demands. Like everybody else, they're doing more with less.

Unconscious biases also can influence how doctors behave. For example:

1. They're reluctant to diagnose bad illnesses in their patients. This can lead to an incomplete list of differential diagnoses.

2. They don't want to make patients anxious. This can lead to insufficient explanations of their thought processes, which can cause patients to feel even more anxious.

3. They rely too much on evidence-based medicine. Science *should* be the standard, but, as Lickerman put it, "[M]any physicians forget that there's a great difference between 'there's no evidence existing in the medical literature to link symptom X with disease Y' and there's no evidence existing to link symptom X with disease Y *because it's not yet been studied.*"

One reader comment to his post spoke to this issue. "As a medical librarian," it read, "I'm partial to ... over-relying on evidence-based medicine -- so true! There just aren't studies on everything & it takes a lot of good studies to come up with the meta-analysis required for evidence-based medicine. And not everyone fits the mold, anyway."

Late last year, long after the essay was posted, another reader weighed in about how some doctors seem too entrenched in their thinking to be great diagnosticians:

"I've been an RN for 20 years," she wrote. "... I've actually been appalled a few times at both physicians and nurses ... the unwillingness to deviate from a preconceived diagnosis, reliance on testing over history and assessment, etc. ... I'm sorry for all the stories on here where people aren't necessarily heard. Doctors and nurses both are under constant, tremendous pressure from every angle and it is understandable (though not excusable) how one may not have the fortitude to withstand personal biases, the easy answers, etc. Refreshing to read this type of article from a physician. ... my recent experiences as a patient have found most of them either wanting to reinvent the wheel or getting stuck on a favored diagnosis when history and assessment clearly discredit both...."

4. They don't like the patient. This can make a doctor impatient and uncommunicative.

5. They like the patient too much. See Nos. 1 and 2.

6. They think the patient's symptoms are caused by one diagnosis instead of many. Sometimes they are, and sometimes they aren't.

7. They want to be right more than they want their patient to get better. No explanation required.

8. They believe their first thoughts about the diagnosis are the most likely to be correct. This can lead to failing to pursue other possibilities.

9. They fail to consider that a test might be wrong. Uncommon, but sometimes tests *are* wrong.

10. They want to avoid feeling ineffectual. Some diagnoses are more treatable than others. No patient wants to have an untreatable illness, and no doctor wants to diagnose it.

11. They're wary of being manipulated. Some patients suffering from chronic pain, for example, are more interested in getting drugs than a diagnosis.

Getting the Doctor on Your Side

A sense of fairness, a sense of humor and a sense of common cause go a long way toward establishing a mutually satisfying relationship. To maximize your doctor's ability to help you, Lickerman also suggested:

Position your symptoms and requests carefully. Don't *demand* medications or tests; ask or wonder about them. Mention research you've done about your symptoms, but express your openness to the possibility that your ideas might be wrong. Be a partner in problem-solving.

Be reasonable even when you're irritated. Most doctors, even those under stress, respond to reason and reasonableness in kind.

If your doctor suggests your symptoms might be due to stress, acknowledge that possibility even if you disagree. The doctor *might* be right, and if you dismiss the idea out of hand, your doctor might become defensive and more committed to an idea that otherwise was only one possibility among many.

Ask questions that promote transparent, logical thinking. Many doctors don't explain their thought processes clearly. But if you organize and write all your questions down before your visits, you can help him or her make a diagnosis. Good questions include: "What possibilities will this test rule in or out?" "What else is on your list of possible diagnoses?" This requires accepting the answers, which sometimes takes courage.

Be explicit about your expectations of the relationship. Show the doctor you're interested in the process of medical detective work. Be a student. As Lickerman noted, "Nothing helps improve someone's thought process like having to explain it to someone else."

Ask your doctor to explain the risks and benefits of any proposed test or treatment quantitatively. Get percentages for risks and compare them to the risks of activities you tolerate every day. For instance, your annual risk of dying in a motor vehicle accident is 0.016%. But many worrisome side effects of drugs occur at an even lower frequency.

Get second opinions. And sometimes third opinions. Or more. But understand that multiple cooks in the diagnosis soup can make you more confused than you were with only one. But don't assume because your doctor doesn't know what's going on that no one else will either. Sometimes it takes several doctors before you find the right one with the right experience to figure out your problem. Let's hope your insurance coverage allows it.

One Lickerman reader commented on the frustration of finding a doctor who could help:

"... I saw twenty seven doctors for what turned out to be interstitial cystitis. ... I found the twenty eighth who immediately knew what I had. But that took three years and the pain and symptoms were so severe I developed suicidal ideation. Every urologist I saw told me it 'was all in my head' but refused to call the psychiatrist I was seeing. ..."

Lickerman responded: "... Good for you for being such a staunch and informed advocate for your own health. You kept asking questions your doctors should have been asking until you found one who was willing to ask them with you. ..."

Doctor, Heal Thyself

"I have a small cadre of patients who suffer from symptoms more horrible than I can describe, some with known diagnoses and some without," Lickerman concluded. "In all cases, my ability to help them is tragically limited."

"Sometimes I want to ignore these patients. Sometimes I cringe when they call, not because I don't like them or because they complain to me too much or because I don't care about them but because I have so little real relief to offer them. I know how much my simply being present and being willing to listen has meant to them ... and I don't discount it. And I do my best to diagnose and treat what problems I can and sympathize with them when I can't.

"But it's hard. I must constantly be on guard not to fall under the influence of all the thought errors and biases I've described here. So while I hope everyone who reads this post finds it helpful, I have to confess that the person to whom I actually wrote it was myself."

Recent Health Care Blog Posts

Here are some recent posts on our patient safety blog that might interest you.

- When more is less: Lots of [advanced treatments for disease are expensive and show no real benefit for patients](#). We summarize some of the evidence in treatments like Tamiflu for flu or advanced life support measures for heart attack, or prophylactic removal of a healthy breast when its mate develops cancer.
- [A primer](#) on what you need to know about Vitamin D, especially in the winter when your body manufactures less because your sun exposure is reduced.
- Experts in cervical cancer are moving away from the Pap Smear and toward [recommending testing for Human Papilloma Virus \(HPV\)](#) as the best way to detect cervical cancer early.

Past issues of this newsletter:

We're now in year SIX! Here is a quick [index of past issues of our newsletter](#), most recent first.

Here's to a healthful 2015!

Sincerely,



Patrick Malone
Patrick Malone & Associates

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