

Mystery Diagnosis: Why Nobody Knows What's Wrong

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Flipping through the channels one night last month, I happened upon the Discovery Channel's *Mystery Diagnosis*, and I found myself captivated by the simple, earnest drama of one woman's struggle with getting well. Hundreds of tests and thousands of dollars later, she learns the truth. It turns out the woman has a disease called Hashimoto's thyroiditis, an autoimmune condition in which the body's immune system produces antibodies that attack the thyroid, causing a decrease in production of vital thyroid hormones.

Mystery solved.

Listening to the story, I was struck by a few things. The first is the obvious message behind the drama: Don't let yourself be told that it's all in your head. There is a *cause*. And so the woman eventually stumbles across a kind endocrinologist who glances at her tests and sees the abnormalities that constitute the "smoking gun" in this patient's particular condition.

The second thing that struck me was how the writers of the narrative documented—and highlighted—the errors of omission. It would be hard to fill a half-hour segment if a few trusted physicians hadn't overlooked a relatively straightforward diagnosis. Of course, there was probably a lot left out. I often wonder when I am seeing a patient what I *haven't* been told. Sometimes a diagnosis is missed because a key test turns up negative at just the moment when the condition is under investigation. Maybe the body compensated for a few days, or maybe the condition is in evolution. In any case, patients have been led to believe everything can be discovered through tests, when in fact it is not that simple (and believe me, we *wish* it were that simple).

Of course, this leads one to consider malpractice, but the cases of individual patients are just that, individual cases, with their peculiar features. Human biology is extremely complex (for that matter, algae is complex too!) and reducing it to simple perfect scans, like Dr. McCoy on *Star Trek*, is just not likely for another hundred years, or perhaps a thousand. It isn't errors of omission or outright malpractice that leads to most claims. It's communication. In studies of why patients file claims for malpractice or negligence, it is most often a break down in the practitioner-patient relationship that leads to action.¹ It made me wonder what sort of communication occurred between this patient and her various physicians.

Is Disease "Material"?

That led me to the third thing that began to trouble me about the story, and I was keenly aware of the hundreds of thousands of people who would view, and learn from, that broadcast. That last thing that bothered me is that the story imparted a message that a disease's cause must be *material*. That is, the cause of all sickness is some physical thing that is deficient, overactive, diseased, broken down, or defective. That's the whole point of *House, M.D.*, that at the end of the day, there's something material, traceable and knowable. The implications is that there's nothing really mysterious about our human existence, and by extension, human suffering. Disease is just an undiscovered tumor, germ, or weak gland.



¹ Huntington & Kuhn. Communication gaffes: a root cause of malpractice claims. *Baylor University Medical Center Proceedings*, 16:2, 157-161; 2003.

Disease as “Character Weakness”

Alternatively, it's human weakness, a defective character, that leads to disease. Alcoholism, smoking, overeating, overwork, street drugs, sloth, all are certainly going to stress the body and the mind. More and more, such behaviors are considered diseases themselves. In the TV commercial, a white, middle-class-appearing woman says, “I have a tobacco addiction...it's a *disease*.”

Then there are the diseases “mind” as in anxiety, obsessive behavior, and attention deficits. Psychiatrists argue that such diseases are either defects of behavior, and people need to be retrained, and that others are problems of brain chemistry, and require drugs. In another TV commercial a man says, “I have social anxiety disorder...” followed by a pitch for one of the serotonin reuptake inhibitors.

A common thread in these quotes from television commercials is that they are all advertisements for drugs. The subtext is that there are definable common cause for the clusters of discomforts we call “diseases,” *and* that we either know what they are, or we are darn close to finding them all out. That's good for marketing, but may be bad for your health—just look at what happened with thalidomide² and Vioxx³, among others. It's not that I believe that people who smoke or people who are anxious in social situations aren't suffering and don't want to be healthier. But I am discomfited by the labeling of complex phenomena as “diseases” with single, identifiable, material causes. In some cases, this may be true. For example, Down Syndrome is caused by a single, identifiable, material cause: an extra 21st chromosome, which leads to a host of genetic conflicts with a range of shared symptoms and features.

I am equally uncomfortable with trying to stuff human suffering into the box of “character defect.” I meet a lot of patients, mostly women but some men, who have been told they need to see a therapist, presumably for some behavior modification or psychoanalysis, after the physician finds “nothing wrong.”

The Box

The Box has two compartments: one for the body, and one for the mind. In traditional health care your problems fits into one or the other. If it doesn't, you're a problem. Theoretical nursing doesn't view things that way. Body and mind are a unity, and the box is a model that limits what we can understand and do. The problem is that this is the “box” within which most disease is thought to exist. It makes for good marketing because drug makers can argue, for example, that, “Tobacco addiction is a disease, and thus you probably need this product to ‘cure’ your disease.” They are often more subtle, using words like “you may need help” or other supportive language—and that's fine, if that is what you want to try. But shouldn't that be a discussion between you and you clinician, and not another simplistic ad aired right before another company tries to sell you potato chips? And should this be a discussion beyond whether you have a defective character, as in, “You have to want to quit,” or whether “You have malfunctioning brain chemistry”?

In case you hadn't guessed, I don't care for “direct to consumer” drug advertising. It's called “educational”, but it isn't. When patients come into my office and ask for the “drug with the butterfly” or “the little purple pill” I have to doubt that anyone is being “educated.” Commercial “education” vastly oversimplifies things, and Merck & Co. isn't interested in a real relationship with you, personally, except insofar as it induces you to fill a prescription.

But back to The Box.

² Thalidomide caused deformities in the limbs of babies born of some mothers who took the drug during pregnancy, but this was not discovered until the drug had been on the market for some time.

³ Vioxx, rofecoxib, was found to cause a disproportionate number of heart attacks in those who took the drug. This was allegedly known by the manufacturers during testing. The case is now in litigation.

It's easy for physicians to decide that "it's all in your head"—if your symptoms don't fit any symptom pattern of a known physical disease. Chronic fatigue syndrome was thought to be "in people's heads" until researchers began to realize that it *is* a real disease—they just don't know *what* it is! The same is true of "fibromyalgia," but once again, trying to create a broad category to collect people's individual suffering, it's still part of The Box. As a result, some drug company decides to trial a drug against the new "disease," and perhaps it demonstrates a result slightly better than placebo. And the game is on. We have a "new" disease—and a new drug with which to "treat" it. So it is both a matter of perspective and a matter of economics how this thing plays out.

Thinking Outside The "Box"

In a previous article I talked about "normal science." This is the science that fits into the dominant set of theories that dictate what is and what isn't appropriate for scientific investigation. Normal science changes with the ages. The Box is part of the normal science of medicine today. In health care, shows like *Mystery Diagnosis* and *House M.D.* play into that dominant scientific model: that there is a definable, *material* problem when someone has a "disease." And if the clinician doesn't find it?

Then it's in your head. It's anxiety or depression or neurosis or delusion.

This is how the tale plays into our usual expectations about health and disease. We have view of illness that's "boxed in" and we often can't see outside the box—let alone *think* outside of it!

For centuries, the cause of disease was at best a guess. Germ theory gave us a sense that some thing that was identifiable caused disease—but germ theory only covered infectious diseases like typhoid or malaria. There was a lot it didn't explain. Pasteur, whose work with vaccines set the stage for modern public health, was to have disavowed germ theory on this deathbed: "Bernard was right; the pathogen is nothing; the terrain is everything."⁴

But what is this "terrain"?

A Control System?

Biology is extraordinarily complex. Take any area of biology—the basis of medicine—and even someone new to the field quickly appreciates just how complex even a part of biology is. Brain function, immunity, kinesiology⁵—any specific area quickly demonstrates not only complexity but also induces us to wonder, how does this all work together? Current medical theory goes something like this: The body is like a really, really complicated mechanical clock. If we just understood all the pieces, then we'd figure it out. (And of course, by extension, we would be able to develop drugs for all those individual tiny problems. A bonanza!) In this model, the mind is a *confounder*, an x-factor that seems to affect what happens in the body, and is mainly the province of psychologists who can attempt to modify adverse behaviors. There can be some teamwork in this model, but it never approaches true holism. So two doctors attack the problem from two different angles, but they never really meet.

Chaos theory, one of the bases of what is now being called "complexity theory," suggests that all systems are inherently chaotic. There is a skeleton of order imposed by the material of the system. In biology, the cells and all their little organelles, their proteins, the electrochemical principles of molecular dynamics, the expression of genes, these are among the features of cellular biology that form the skeleton. But there are too many "loose ends," too many redundancies, and too many seemingly random cellular acts to account for how the system runs efficiently—when it's healthy. The Figure outlines an idealized system.

⁴ Claude Bernard (1813-1878), French physician and researcher. From Coulter. *Divided Legacy: A History of Schism in Medical Thought, Volume II*. Berkeley CA: North Atlantic Books.

⁵ The study of movement.

The system depicted could be anything, a brain function, a pain signaling system, some part of immunity. It doesn't matter. What is important to note is that there are two hypothetical results, A and B. It turns out that each is necessary at different times and for different reasons. It also turns out that there's in initiation step, labeled Process step 1, that gets the ball rolling.

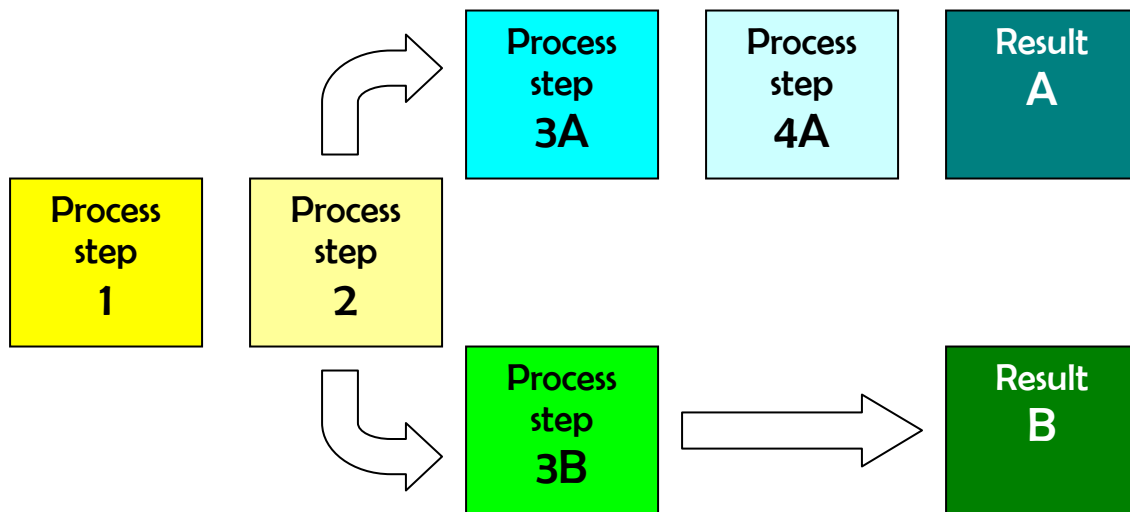


Figure: An Idealized Small Scale Body System

Typically, this step arises from some stimulus, either from within or outside the body; it's a response to something else, and it too is evolutionarily necessary.

Note that the process unfolds step 1 to step 2. This is how biologists would like to reduce the body, reduce *us* to simple connected processes. It is a way of thinking that admits no "chance" no randomness. But the randomness is there nevertheless. Look at Process step 3—it can go either way. Today's normal science is still convinced that some material factor determines which way the process will unfold, A or B, and thus what happens downstream. Chaos theory suggests that there are many systems in which *nothing material* is required to steer the system to respond one way or the other. In such a model, we'd be nothing but a pile of chemicals—if it *were* completely random. So what keeps us going? What keeps the system in line?

By now, we've pretty much ruled out that the system is like a "clock." Current researchers are looking at genetics as the control system, but as biologist Rupert Sheldrake suggests, there just aren't enough genes to account for all the control that would be necessary to make this system, your system, work as well as it does, as there are millions of "subroutines" that are vastly more complex than the simplified, idealized system I have drawn above. Sheldrake states that there aren't enough genes to account for all the subtleties of biological form, and I argue that this is also true of biological function.⁶

So is disease a defect of "terrain"? And is terrain really the control system that ties it all together, a subtle energy that helps the system choose A over B, or B over A? Nurse healers assert that we are surrounded by an "energy field" that animates us, keeps us "together" and helps the system to function. In Chinese medicine there are "meridians" of energy, or "chi," that flow through us; disease is caused in part by blockages of or changes in this flow. In homeopathy it's been called the "vital force." In all of these medical traditions, healers argue for the existence of something that keeps everything together. Is this the cause of disease? And if so, is *this field* what we need to understand in order to help people heal?

⁶ Sheldrake. *A New Science of Life*. Rochester VT: Parke St. Press.

In Your Head or In Your Body...

Disease, “dis-ease”, is personal. The thing that the healing systems above have in common is that they recognize that. Often, simple things *are* at fault, and it seems increasingly common to me that simple things are missed. Sometimes, it *is* the weird “mystery disease” that will respond to a simple removal of the cause, or a supplement, like a vitamin. Yet one must ask, what went wrong with the system in the first place? Why did Result B overcome Result A? In many cases, the cause is really unknown. I want to suggest that perhaps theoreticians in these other medical systems have intuited what we, as patients, sometimes suspect on our own. More plainly, maybe it is this subtle control system that gets “out of whack.”

Going back to our woman on *Mystery* Diagnosis with Hashimoto’s thyroiditis, it *is* fairly easy to diagnose and treat with traditional medicine, and in fact often also responds to homeopathic medicine, avoiding the need for lifelong treatment. Of course, such a disease, if unresponsive to a brief attempt to treat it homeopathically, can be treated with mainstream medicine, an ecological approach. What is really interesting is that it may respond to other systems. Chinese medicine is fairly obvious—the acupuncture needles and herbs are material treatments that are easy to understand. What about shamans, nurses, and so-called “spontaneous” remissions? I have had patients who were suffering in extraordinary ways at some point in their history, and have sometimes been told that they were “healed” by “witch doctors” or “the Lord Jesus.”

Without getting into a strictly religious discussion, it has become clear to me that a person’s experience, the wholeness of their body-mind-spirit, works as a unit, and that viewed this way, most things are possible, because it covers all the pieces: the material *and* whatever subtle control system has gone awry. In a patient of mine: What made the thyroiditis “go away”? Was it a remedy or an acupuncture needle that tripped a change in a small system from A or B, or B to A? Was it God? Was it a field effect exerted by a powerful intuitive healer?

It goes beyond a disease like thyroiditis, though. There’s a much greater array of the experience of human dis-ease than the thousands of labels available to categorize people’s suffering listed in the *International Classification of Diseases, 10th Edition*. And most of the time, the “problem” not the dramatic, exotic diagnosis portrayed on shows like *Mystery Diagnosis*. More often than not, chronic complaints are a result of dysfunction in the entire unity the body and the mind, what some term the “bodymind,” the material *and* behavior. Real healing work then must involve stepping forward into a genuine curiosity about that whole, and this includes both an understanding of the “pathology” of the subtle energetic system as well as the material system. Moreover, it asks that clinicians be willing to explore therapeutics for the *energetic* as well as the material and behavioral aspects of health and disease.

I think shows like *House M.D.* are fun. I watch them sometimes. But I do get troubled that they tend to reinforce what’s in The Box. And it is nice to pick up the missed-but-obvious material diagnosis that requires a simple material—drug or surgical—fix. Even founding homeopath and physician Samuel Hahnemann understood that. Nevertheless, if John Smith asks me, “So what is it? Fibromyalgia? Lyme disease?” I will answer, “You have ‘John Smith’ disease. No one else has ever had it and no one else ever will. It is unique.” I view my job as trying to find what homeopathic remedy is most like “John Smith disease” and use that to affect the subtle energy system. Sometimes that is enough.

Nursing and Healing

Nursing teaches us that people are complex, holistic beings, they are “bodymindspirit” and that we have to approach them that way. Case management, that is, invoking different services such as medicine, physical therapy, and therapeutic communication, is the most commonplace and readily understood means to see this work in helping patients improve.

Nursing recognizes that curing is desirable but ultimately impossible—we *all* die of something!—and that our duty is to “walk with the patient,” curing when able, adapting when we must. Nursing brings together the material with the ephemeral. It works with the body but admits the existence of the energetic (even if we don’t all agree on what the energy is). And while nursing is sometimes dramatic, more often than not it is patient, complex, itself subtle. In this way, it doesn’t make for good television. However, if we are to get beyond our current state of affairs, we will have to make room in our minds for something beyond the drama of the material. It is in our mind, or our body, or our spirit? Maybe it is, in varying measures, in all three. This is the charge for 21st century healing. Be well.



The Arch in Chinatown, Philadelphia. A Chinese medicine shop. Pharmacy case. Photos: Author.