What You Don't Know Can Hurt You • A Guide for Patients

Help for Navigating Medical Information & Making Informed Decisions

Delfini Group Evidence-based Practice Series
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About Our Book + Some Stories From Our Book + Why We Can Help You

Imagine that you are taking a walk in the woods. You come to a fork in the road, but the way forward is covered by a dense cloud bank; one so thick that you can't see more than a few steps ahead. What you do see, however, is that there are a lot signs directing you one way, and the path looks well-trodden. The other path looks far less traveled, and there are no signs inviting you to choose this other path.

If you truly are in the woods, probably you will opt for the well-traveled road. In the health care world, we all tend to do that too. Doctors, other health care professionals and patients alike. However, sometimes the typical pathways—even with advice from those with the best of intentions, such as the best doctors and other health care professionals—can lead you right off a cliff.

Here's the cliff: A lot of medical science is not reliable or is of uncertain reliability—most physicians and others advising you about your care do not know this or know how to tell—if they are even using science-based information at all. In addition, most physicians and others advising you about your care do not present you with sufficient information about all your options.

The stakes are high and the consequences can be costly—even deadly.

We want to help you avoid the cliff. We have written our book to help you steer away from danger and toward meaningful health care information that enables you to be a truly informed patient—one who has reliable and sufficient information to make medical choices that are the ones you want. Choices based on your personal requirements. These include your health care problems + your own special circumstances + your values + your preferences which all inform your health care needs + wants.

Imagine That You Have A Medical Problem...

You have a medical problem. You seek a solution. A recommendation is made and a pathway is presented to you. It is your move to take the next step. But should you? That is what this book is about. *Should you?* Or should you navigate differently? And if so, *how* do you do so?

Our book is about the need for you to sometimes change the pathway you find yourself on based on the medical information you receive—or have not received. It is about the importance, at times, of changing the course of your conversation with your doctor or other health care providers so that you better understand your options and their potential consequences.

It can be an easy journey or a complex one to arrive at a health care decision. For the good of your health, we are about to make it somewhat more complex. What most people don't know—and what you *need* to know—is that there are some enormous problems and pitfalls plaguing **health care information** and **health care decision-making**. And when we say most people, *surprisingly*, this includes most doctors and other types of health care professionals who are involved in helping patients make medical decisions. The likelihood is high that this includes *your* doctors and others who are assisting you in your health care choices. These problems are shocking, they are shockingly common, they are entrenched, and many people have been harmed as a result. We hope to make things better for you.

The information and tools provided in this book will help you think through your health care decisions. Having a chance at being successful requires that **you participate** in making informed decisions—even if that means an informed decision to let your doctor decide on your behalf.

Oxford scholar and BMJ blogger, Dr. Richard Lehman writes:

> "Wherever we look in clinical practice, **the evidence we have is often a poor match for the evidence we need**. To conceal our ignorance and save us the trouble of dealing with uncertainty, we often behave like Procrustes when he invited guests to stay the night. If they were too short for his bed, he stretched them to fit: if they were too long, he cut a bit off them. One-size-fits-all treatment means that most of the prescribing we do e.g. for raised blood pressure, or for systolic heart failure, does very little good. **We make the patients fit the evidence, shoving square pegs into round holes**, especially if that earns us money. We need a different way of generating evidence and of practising medicine."

We hope that reading our book can improve your care and potentially even save your life by giving you some simple guideposts to help you. We want to give you help to dispel the cloudiness of health care so you can see more clearly and avoid danger. We want to give you guidance and tools to help you pick the right path for you.

Our book is dedicated to all the patients, doctors and others who have found themselves on the wrong path in health care, our book is dedicated to all of us being able to find our way through a dark wood...

What Happened

"The Pain of Arthritis"

"So Ms. Bodie, I'm switching you to a different treatment for your arthritis. I've always been concerned that the drug we're currently using for your pain management could harm your stomach lining especially at the dose you've been using, and that could be very serious. But now there's a new drug that significantly cuts down this risk. I believe this drug is safer, and I'm seeing *excellent* pain relief in my patients who are using it. The results I'm seeing are *so* good, I am convinced that it's even better for pain relief compared to what you're taking."

Ms. Bodie startles a little. *Always* concerned? Her doctor has never said anything to her about this before now, and he was the one who recommended this treatment in the first place. She first came to him when she started having joint pain that made walking and gardening uncomfortable. He recommended her current treatment without hesitation. She vaguely recalls hearing somewhere that some people had developed ulcers on her drug, but she didn't pay much attention, assuming that this was some rare event that didn't pertain to her—she can eat anything! All drugs seem to have such a long list of potential side effects and, since most people seem okay taking them, she just assumed all this excess was for legal reasons. Besides, the medication she is using is so common. It isn't even a prescription drug; she gets it over-the-counter. Doesn't that mean it's safe?

She calms herself by running a little internal dialogue in her head, reasoning that nothing has happened to her—everything is okay. He is just being cautious in the face of a new drug becoming available. Even if he had told her about this risk, she would have taken her current medication anyway, she tells herself. And she was right to do so. She's had no stomach problems, and life has been so much better because of her medication. She's been able to resume, pain-free, the daily activities that are so important to her. They are now having this discussion because there is some new alternative he's just learned about that will be better for her—so this is just about "new and improved." She smiles and thanks him.

Dr. Meddi rapidly fills out the script and sends it electronically to the pharmacy. "The pharmacist will give you instructions for using it," he says, rising. "Plan to check back with me in six months, unless you need to come in sooner. Always good to see you, Ms. Bodie," he says, one hand warmly placed on her shoulder, gently easing her toward the door just beyond which she can hear a couple of babies crying—participants in the throng of humanity that always fills the waiting room of this popular, intelligent and compassionate doctor.

On the face of it, what we've just presented to you is a fairly typical patient/physician encounter in a fairly typical day—a caring physician, a patient with a common problem, a medical decision decided upon in a fairly typical way. If you were in Ms. Bodie's shoes, our bet is that you too would thank your doctor, go fill your prescription at the pharmacy—and then experience more than a slight shock when you found out that you now have to pay over $60 for a month of treatment when you had been paying less than $5 before! That's $2 per day of treatment as compared to a mere 5 cents! As you stand there blinking in surprise as your arm slowly rises toward the pharmacist, credit card extended, you would mentally calculate how you are going to accommodate this new hit on your budget.

But also, in all likelihood, you would simultaneously be bolstering yourself to accept your new expense with at least a modicum of gratitude and grace. You didn't know you were facing such risk. And over a drug so cheap and

common and in quantities so plentiful—available at your grocery store, where even *children* can buy it, for heaven's sake—that you never thought of it as particularly harmful!

This new drug your doctor has just prescribed for you will help you avoid a serious problem that you didn't even know you were risking. Who wants to end up with an ulcer? You would likely try to soothe your disappointment by telling yourself that staying healthy and pain-free is more important than the dinner out once a month that you will now need to cut from your expenses. With a wrecked stomach lining, there would be no dinners to enjoy...

And you might also experience a slight whiff of *disaster avoided* now surrounding you and coloring your mood. This might make you feel a bit relieved and congratulatory—dodged *that* bullet! And perhaps it might not—making you feel a tiny bit better, but also making you feel slightly uncomfortable, feeling more vulnerable than you already thought you were. Life just got a bit more uncertain; the ground you are standing upon, a bit more shaky and a bit less solid.

We are about to shake things up a bit more. What if we told you that, what seems here to be a common patient/physician exchange, is lacking in several ways important to *quality* patient care—and in ways that can sometimes result in serious harm to patients in a multitude of ways? Often *unnecessarily*. We want to show you how, if you were in Ms. Bodie's place, you might be able to turn the encounter in a direction better for your health—or at least in a better direction for *your* making a *decision* about your care. How can you enhance health care decision-making through improving your chances for optimal **information** and **engagement**?

We Want To Improve Your Health Care Decision-Making

There are quite a few things that went wrong in this medical encounter. But if you made note of the fact that no scientific information supporting the new drug was provided to Ms. Bodie, you are well on your way to being an informed health care decision-maker.

At times, to get high quality health care involving interventions, you need high quality scientific information, and you need this information provided to you effectively so that you can make decisions that are right for you. You need to know the quality of the science. You need meaningful—and not misleading—quantified information about the probability of benefits and harms that you can understand. You need to know if the research participants studied are similar to you or not. If they are not similar to you, the outcomes may be more unpredictable.

Our plan is to show you examples of how a patient might shift the course of a medical encounter to improve his or her chances of getting information that is likely to be helpful. In these examples, these patients will do this through the **7 questions** we have created for you, and they will do this by actively encouraging their care providers to, "***Please, tell me a little more***."

What Happened: Part II

"The Pain of Arthritis" Deconstructed

Let us go back to our case study of Ms. Bodie and Dr. Meddi. What if we told you that, as a result of following her doctor's advice to switch to a new drug, Ms. Bodie *died?* And we are not talking about some weird quirk of fate due to some odd allergic reaction to which she was uniquely prone (albeit always a possibility) or some problem

with dosing or some bad synergistic interaction between drugs, food or something other in conflict with her new treatment. We are not talking about something strange and random and peculiar. We are talking about a straight-up preventable death, had the right actions occurred, and that—for tens of thousands of people—did not. In fact, we are talking about an **estimated preventable 140,000 heart attacks and 60,000 deaths** from the the use of a popular painkiller, now pulled from the market because of patient safety issues. And yet the information about patient safety was easily available to prescribing doctors whom we believe did not know how to interpret a couple of easy-to-understand results—and did not communicate this information to their patients.

So should have happened??? Let's look at the interaction between Ms. Bodie and Dr. Meddi and break it down bit by bit. We are going to state again that Dr. Meddi is an intelligent and compassionate human being. He cares about Ms. Bodie very much and wants the best for her. But he is practicing an outdated form of medicine that is very traditional, very typical and—in many ways—very wrong. Our criticisms are not of him, but of the approach that he learned long ago and which is engrained in him after many years of practice. And which, by the way, is common with many new physicians too.

At the start of the encounter, what we see is a paternalistic approach. "*I'm* switching you," he says, (emphasis ours) and then proceeds to explain his reasons and what new course of action he will prescribe. His rationale is based on a concern about patient risk—which, on the face of it, sounds good. He remarks about alternatives—again this sounds good. He is up on the latest—"now there's a new drug..."—sounds good, right? And he states that he has experience with this new drug, seeing beneficial effects in his patients. How can this *not* all be *very* good?

Ah yes, and he treats Ms. Bodie warmly and respectfully throughout. Well, he got that one thing right! Okay, what's *wrong?* Well, actually a lot.

There are times when medicine is necessarily "paternalistic," with the doctor "knowing best" and making the calls. But, in fact, medicine should usually *not* be paternalistic unless you are unconscious, for example. It should be patient-centered and patient-driven—*you* should have the opportunity to make the calls about your own health care, hopefully supplied with reliable and useful information.

Patient-centered care means care in which *you, as a unique person*—not simply a disease or condition or a problem—are at the center of your care experience. Clinicians are frequently not adept at eliciting information from patients to discern their own individual requirements. Further, your doctor making a decision for you might not be the one you would make if you had all the information you needed. Studies have shown that doctors' guesses and assumptions about what decisions patients prefer are often very wrong, patients often being generally **more conservative** in their choices than doctors think they will be.

Concern for patient risk is important, of course. But in this particular case study, Dr. Meddi, in fact, overlooked two critically important issues about risk: 1) risks of new treatments are often not known until much later after being used by many people over time—if they are ever known—yet, in this case, they were discovered to be even larger and more deadly; and, 2) in this particular example, the increased risk of heart attack was apparently not considered by him.

While Dr. Meddi remarks about alternatives, he didn't share information about these alternatives with his patient. He has said nothing about the quality of the science for any treatment, nor has he discussed the benefits, harms and other issues associated with them. So Ms. Bodie really gets no information about potential choices she might have.

Lastly, he tells her that he has witnessed good pain relief outcomes with this new drug—he is even convinced the new drug is superior to her current treatment. Well, bluntly, often we see what we want to see. If the outcomes he is seeing with his patients are truly dramatic—well, maybe. But it could be that he is hearing biased reports from his patients who believe new is always better, or they want to please him, or they think this drug had *better* be superior for their pain at $60 a monthly pop! But often, we are fooled by our observations. Often you really *don't* know what is causing something, unless you have immediate and consistent results (and even then, you can be wrong)—but humans being humans, often you think you do "know"—and doctors are no different and often mistakenly think that they have figured out cause and effect.

Why A Different Kind of Conversation With Your Doctor Might Save Your Life

As a benchmark, consider—the lives of an estimated 58,000 US citizens were lost in the Vietnam War over, roughly, a ten-year time span. We have already told you that use of a popular painkiller may have contributed to an estimated 140,000 heart attacks and 60,000 deaths in the US over a four-year period of time.

Further, another estimated 63,000 people in the US, treated by cardiologists, died over a seven-year timeframe from a type of treatment that roughly half of all the cardiologists in the US were prescribing, but which had no good science to support it.

From the use of just these two therapies in the US alone, we are now up to over 123,000 preventable deaths that may not have occurred had prescribing physicians better understood some basic medical science principles, the potential consequences of not applying them and communicated some key facts to patients. For just two treatments! There are many more such examples.

But if you apply our suggestions in our book, you may improve your chances of getting high quality care and avoiding these kinds of harms. We help you understand some big pitfalls in medical science and in medical communications. We help you with ideas for navigating differently to help achieve the health care that is right for you.

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