

CHAPTER FIVE The Mushroom Treatment

You are often kept in the dark about how likely it is that a proposed treatment will actually help you, and about what kinds of problems it might cause you. Doctors rarely provide this basic information, and instead often expect that you will simply follow their instructions. This approach endangers your health and well-being.

Treatment

One year, I had a DEXA scan, a test to see if my bones were thinning. It turns out that the prescription for the test was based on an error in the doctor's office. According to her records, I had shrunk two inches between visits. My husband started laughing when I told him about this latest medical evaluation. "Not unless I've also shrunk two inches," he said. "You still fit under my chin exactly as you always have."

Subsequent measurements proved him correct. In the meantime, I had the test. I couldn't see what harm a simple diagnostic test could have, so I didn't push back. The doctor called me after she got the test results and prescribed a drug. Call the prescription Drug A. It was heavily marketed by the drug company that sells it.

A month later, I returned to the doctor with severe pain in my buttocks. The doctor added prescriptions for Drugs B and C. A month after that, the pain was so severe that I was entirely unable to ride my bicycle or even swim. I felt disabled. Dealing with a typical day in the office was very difficult. Business travel was agonizing. The doctor sent me for hip x-rays to see if I had somehow broken my hip. I had not.

The doctor doubled the dose of Drug C. Four months later, with the pain still severe, she added two more drugs, D and E, to the treatment regimen. I had entirely stopped exercising due to the pain. I had gained weight. In the following two months, I had ten visits to a chiropractor for back pain.

The next month, I had such severe gastrointestinal pain that I was unable to eat anything at all for about a week. Around the same time, I reviewed my care with a highly skilled doctor, an internist I was lucky enough to have had access to at work.

He was startled that I had been prescribed *any* drug based on the DEXA scan: my test results did not fall into the range for which the drug was considered appropriate. He recommended stopping all five drugs. I did so. Within a few weeks, all of the excruciating pain and disruptive disability were history.

In the years following, reports surfaced about side effects of the five drugs the doctor had prescribed for me, explaining all of the nearly year-long distress I had experienced. One of the drugs, in fact, was subsequently taken off the market.

A follow up DEXAscan a year after that showed that my bones had in fact strengthened. The drug had worked. But that gain essentially cost me a year of my life. If I had understood at any point that it was the cause of my suffering -- in conjunction with the four drugs added to deal with the harm it was causing me -- I would never have taken it.

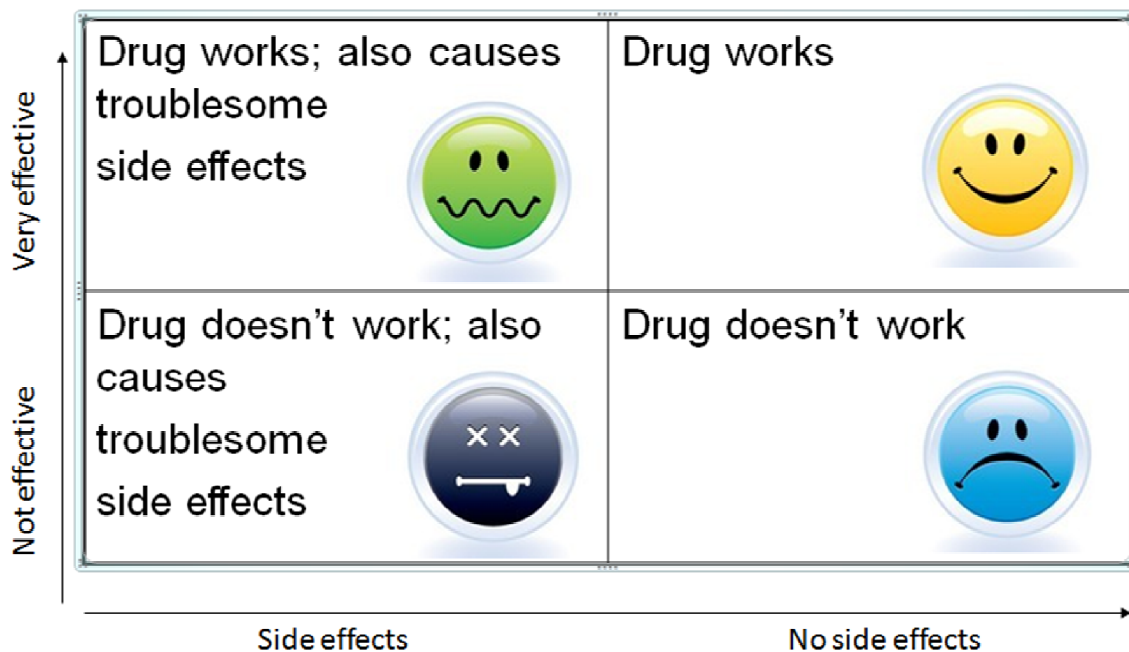
Two Questions

When the doctor prescribes a treatment for you, two questions you might have regarding its impact on your health are:

- Does it solve my problem?
- Does it create other problems?

Those two questions suggest four possible outcomes, as shown below. For the sake of illustration, assume that the treatment in question is a drug to treat a chronic condition.

When an Individual is Treated



Best Box

The box in the upper right is a great place to be: the drug solves your original problem and doesn't create any others. That is an excellent result.

However, across the health care industry, data suggest that on average, only about 50% of the people benefit from any particular treatment. That fact means that the other 50% fall in one of the two boxes in the bottom half of the chart.

Three Other Boxes

In the bottom right-hand box the drug doesn't help, but it doesn't cause any serious side effects either. That doesn't sound so bad. But if individuals are being treated because their condition requires it, and the drug isn't working for them, presumably they are likely to get sicker. Additionally, a great deal of money is being spent without yielding any benefit. That money then can't be spent on more useful things.

More than 4 *billion* prescriptions are written every year in the U.S. -- nearly 15 for every man, woman, and child in the country.¹³⁸ They cost \$270 billion dollars.¹³⁹ If 50% of the time the drugs don't work for people, then roughly \$135 billion dollars are being wasted. The bottom right-hand box is not a great place to be.

In the bottom left-hand box, the situation is even worse. Here, the drug not only doesn't solve the original problem, it also creates new ones. For example, many drugs are known to cause significant weight gain in many of the people who take them. That alone can cause serious health problems.

In the upper left-hand box, life gets complicated. Here the drug solves the original problem -- and creates other problems. That was the case for me in the example above. Here, the best option is for doctors to work closely with people for whom they've prescribed the drugs. They can adjust the dosing and make other changes in an attempt to reduce side effects while still producing most of the benefits of treatment. That's often very tough to pull off.

Focus on One Box

Every person taking any drug will land in one of these four boxes. In only one of those boxes should individuals almost certainly be encouraged to continue taking the medicine. The half of the people who fall into the bottom two boxes shouldn't be taking the drug at all, and many of the people in the upper left box shouldn't either.

However, it is very common in health care for professionals to talk and act as if there is only one box: the one in the upper right, where only good things happen. Here's what one insurance company wrote to its enrollees: "Taking medicine is an important part of staying healthy. It's very important to take your medicine exactly as ordered."¹⁴⁰

On a similar note, a doctor writing in a prestigious medical journal opined, "Our success or failure in combating osteoporosis increasingly depends not so much on the drugs available to us but rather on our ability to engage our patients and ensure that they take the medicines we prescribe."¹⁴¹

Researchers at the Mayo Clinic discovered that after people went home from the hospital with new drug prescriptions, “only 11% reported that they had been told of potential adverse effects.”¹⁴² Other research similarly concluded that “providers often neglected to tell patients about the potential disadvantages of treatments or tests that they recommended.”¹⁴³

Thus, when health care professionals talk about you and prescription drugs, they tend to talk about coming up with the right carrots and sticks to drive you to take the drugs that doctors have prescribed for you. They call this idea “compliance” or “adherence.”

Given that there are *four* boxes on the chart, it becomes obvious that your health is more likely to improve not as a result of your simply following doctors' orders, but instead by your taking a more active role: as CEO of your own health and health care, figuring out which box you fall into.

CEO's Questions

CEOs don't know everything. They rely heavily on experts, all of whom know more about their field of expertise than the CEO does. What the CEO does know is what questions to ask. In this case, those might include:

- “What is this drug intended to do?”
- “*How* will we know if it's working for me?”
- “*When* will we know if it's working for me?”
- “What big problems should I be watching for, and what do I do if they occur?”

It's hard to be a successful CEO without good information. A logical question to ask is whether individuals are getting this kind of information from their doctors.

Who Knows?

In one study, doctors agreed to be recorded during patient visits as they prescribed drugs new to those individuals. Knowing that they were being recorded, doctors presumably were on their best behavior. Here is the percent of time that the doctors gave people the following critical pieces of information:

- reason for taking the drug: 87%
- name of the drug: 74%
- how often to take it: 68%
- how much to take each time: 55%
- side effects: 35%
- how long to keep taking the drug: 34%¹⁴⁴

Assume that the doctors studied were all equally likely to perform at the above levels with every individual. The odds that any given person was told all six pieces of information are less than

3%.¹⁴⁵ The problem with that result is that people taking the drugs need to know all of these things.

Consider one of the higher percentages listed above: doctors told people the name of the drug 74% of the time. What difference does it make that they didn't tell everyone? Think about adverse drug events, discussed in Chapter One.

Who is present 100% of the time when a drug is being taken? It's not the doctors. It's the patients. How can they help prevent adverse drug events *that can kill them* if they aren't even told the name of the drug they are supposed to be getting? A quarter of the people weren't told.

If you aren't told the reason for taking the drug, the case with 13% of the individuals in this study:

- How could you have taken part in deciding whether to start taking it in the first place?
- How can you play an active role in figuring out if the drug's benefits outweigh any side effects?
- How do you take responsibility for managing the condition the drug is intended to treat?
- How likely are you to keep taking it?

Clearly, the necessary conversations are not happening. If health care were focused on you, a lot more attention would go into helping you figure out which of those four boxes you fall into, and advising you accordingly.

Connect the Docs

Curious about why doctors don't talk about side effects more often? The following experience suggests one reason. A Harvard Medical School student wondered why his professor so enthusiastically promoted cholesterol drugs, "and seemed to belittle a student who asked about side effects."¹⁴⁶

It turned out that "The professor was not only a full-time member of the Harvard Medical faculty, but a paid consultant to 10 drug companies, including five makers of cholesterol treatments."¹⁴⁷

Ties between doctors and manufacturers are common, and concern about them is increasing: "Federal health officials and prosecutors, frustrated that they have been unable to stop illegal kickbacks to doctors from drug and device companies, are investigating doctors who take money for using these products."¹⁴⁸

"The move against doctors is part of a diverse campaign to curb industry marketing tactics that enrich doctors but increase health care costs and sometimes endanger patients."¹⁴⁹

Doctors surveyed, by the way, believe that individuals should turn to them as the best source of quality information about drugs.¹⁵⁰

Making the situation worse, “When patients feel they might be having an adverse drug effect, doctors will very often dismiss their concerns.”¹⁵¹ “Physicians seem to commonly dismiss the possibility of a connection . . . even for the best-reported adverse effects of the most widely prescribed class of drugs.”¹⁵²

“Your bones are thinning.”

After that first DEXAscan, I had two more over the next five years. By this time, I had switched to a new primary care physician, Dr. Wall.¹⁵³ She had been written up as one of the best family care practitioners in the state. She is intelligent, hard working, and thoughtful. Yet here is the entire communication I received -- via recorded message -- after the last DEXAscan: “Your bones are thinning. You need to start taking Drug A, [dosage and frequency].”

That was the same drug I had taken a few years earlier, with terrible side effects. I called her office and eventually connected with someone who was willing to answer questions, although I did not manage to get a live conversation with Dr. Wall herself.

“I need more information than I received in the voice mail I got about the DEXAscan I just had.”

“It says here that your bones are thinning. You need to start taking Drug A.”

“Yes, I got that message. I need some other information. For starters, what is the diagnosis? Do I have osteoporosis? Or is the diagnosis still osteopenia?” (Osteopenia is often, but not necessarily, a precursor to osteoporosis, which is a serious condition that can lead to bone fractures and other potentially disabling outcomes.)

“You have osteopenia.”

“Okay. Good. And what are the actual test results?”

“Your bones are thinning, and you need to take Drug A.”

“What I mean is, what are the numbers given in the report of the test?”

“I don’t know. I’d have to find the report.”

“Okay. I’ll wait.”

“Well, I might not be able to do that . . . I don’t know if that’s in your chart.”

“Okay, I’ll wait while you look.”

“Well, hold on.”

“Okay, thank you.”

After a long wait, she read off a series of numbers. Among these was, “It says T is -2.1.”

“Okay, and how does that compare to the last time I had the test?”

“I don’t know.”

“Could you look it up?”

“I don’t know if we have that information.”

“Yes, you do. Dr. Wall ordered the previous DEXAscan three and a half years ago. You have the results from that test. I’d like to know what the numbers are from that test so I can see how much they’ve changed in three and a half years.”

After a longer wait, she read off the numbers, including, “T is -1.7.”

“Thank you. What other treatment options are there? I cannot take Drug A. It was prescribed for me years ago and I experienced severe side effects. What other options do I have?”

“There isn’t anything else. The only way to treat this is with one of these drugs, and they’re all the same. Your bones are thinning and you have to start taking Drug A, [dosage, frequency].”

I ended the call, exasperated that there had been no discussion with me about options for a workable treatment plan -- just an order for a drug that I knew I couldn’t take. Experiences like mine are common. One study concluded that patients had a voice in treatment decisions only 9% of the time.¹⁵⁴

Mushroom Treatment

It may feel to you as if the treatment you’re getting most consistently regarding the course of action prescribed for you is the “mushroom treatment” -- kept in the dark and fed manure.

The balance of this chapter provides details behind some of the information summarized above.

Coin Toss

The percentage of people who benefit from a treatment varies. For some treatments, it might be as high as 80%. For some, it might be as low as 30%. On average, it appears to be roughly 50%.¹⁵⁵

For example, one drug company’s press release announced that up to 30% of patients saw their pain reduced by half as a result of taking their drug, compared to 15% of patients who improved that much while taking a placebo¹⁵⁶ (pills that don’t have any actual drug in them, commonly

called “sugar pills”). Those numbers seem to imply that only 15 people out of 100 get significant benefits that they wouldn't get without the drug.

Before you page through the endnotes to find out which drug it is, note that it doesn't matter -- the story would be very similar for many drugs, for many kinds of surgery, and for many other treatments as well. Here is another example: a new drug “normalized glucose levels in 51 percent of those who took it, compared with 30 percent in the placebo group.”¹⁵⁷

Here is how one writer summarized the data: “Difficult risk-benefit questions surround most drugs. . . . One dirty little secret of modern medicine is that many drugs work only in a minority of people.”¹⁵⁸

When a doctor orders a treatment for you, she doesn't typically have any idea if you're one of the roughly half who will be helped or one of the half who won't. She typically doesn't tell you that there's a good chance the treatment won't help you at all.

Success rates and side effects for surgery appear similar to those for drugs. As one example, the Blue Cross Blue Shield Technology Evaluation Center concluded that a particular kind of back surgery was successful 57% to 64% of the time.¹⁵⁹ Another analysis, published in a journal for bone surgeons, pegs it at 64%.¹⁶⁰

There are side effects to surgery as well. For instance, according to Dr. Nordin Hadler of the University of North Carolina, coronary bypass surgery carries a 1-2% risk of death during the surgery, and up to a 40% chance of permanent mental decline.¹⁶¹

One Percent

When a drug is prescribed for you, do you have any idea what it is supposed to do and how much it is supposed to help you? For example, if the doctor says that you are at risk for a stroke and that taking this drug reduces that risk by half, does that mean:

- Out of 100 people at risk for a stroke, 100 will end up having a stroke without taking this medicine or something similar; with the medicine, only 50 of 100 will have a stroke?
 - Out of 100 people at risk for a stroke, 2 will end up having a stroke without taking this medicine or something similar; with the medicine, only 1 out of 100 will have a stroke?
- These both represent a 50% reduction in stroke risk.

The second of the above examples is more representative -- one person in a hundred may benefit from a drug taken to forestall complications of a chronic condition.¹⁶² For one diabetes drug, which had sales of \$2.6 billion in one year, an almost infinite number of people would have to take the drug for one person to see a reduction in the consequences of diabetes.¹⁶³

If the only boxes on the chart were the ones on the right -- if there were no downsides to drugs -- then one might be less concerned about numbers like this. But side effects abound, putting a lot of people in one of the boxes on the left-hand side of the chart.

A Hundred Pounds

To illustrate that side effects are a big part of the picture, this section provides more detail for one side effect: weight gain.

In talking about one class of drugs, The National Institutes of Health said, "Concerns have emerged in recent years that some of the newer medicines . . . can cause extreme weight gain, worsen cholesterol and lead to diabetes."¹⁶⁴

Other researchers at well-respected medical centers echo these concerns. For example, an article reporting on an interview with the Director of the Johns Hopkins Weight Management Center noted, "Weight gain can range from a few pounds to more than a hundred pounds. . . . This excess weight is dangerous because it can cause or worsen problems like high blood pressure, other cardiovascular conditions, diabetes, high blood cholesterol, and osteoarthritis."¹⁶⁵

A WebMD article noted, "Certain prescription drugs . . . can cause weight gain -- sometimes 10 pounds a month. . . . Experts estimate the list [of prescription drugs that can cause weight gain] includes more than 50 common medications. . . . Medication-associated weight gain can be modest -- or as much as 30 pounds over several months."¹⁶⁶

A Mayo Clinic researcher commented, "Many physicians considered a drug's weight gain side effect to be a necessary evil . . . or assumed that only weight gains of 100 pounds or more were worrisome. But drugs that lead people to put on just 10 or 20 pounds a year, if taken for many years, can add up to big problems over time."¹⁶⁷

Weight gain is only a problem if it's more than *a hundred pounds*? Doctors routinely tell patients that *losing* just 5-10% of their body weight can result in huge health improvements.¹⁶⁸ For someone who weighs 200 pounds, that's 10-20 pounds. It is surprising that many doctors have dismissed as unimportant *gaining* five to ten times as much weight.

One woman whose diabetes drug led to a 70-pound weight gain said, "I've been overweight my entire life. The last thing I needed was to gain more."¹⁶⁹ But the doctor who prescribed the drug apparently never discussed this side effect with her. He had five years to do it -- that's how long he kept her on the drug.

The most likely explanation is that the doctor is accustomed to considering only the actions he takes (prescribe the drug). The doctor is not accustomed to considering the patient's resulting experience, which in this case almost certainly included a worsening of her health.

When she changed to a new doctor, he changed her drugs. Over the course of the next year, she lost the 70 pounds. For many people, however, once weight is gained, it is never lost.¹⁷⁰

In fact, given the volume of drugs prescribed in the U.S., one wonders what percent of the obesity epidemic is a direct result of drug prescriptions. Half of the adults in the U.S. report taking prescription medicine daily.¹⁷¹

Be Wary

In an article titled, "Be Wary of Narcotics to Treat Back Pain," *Consumer Reports* notes that such drugs often don't do much to help the pain.

At the same time, "Clinical trials have shown that about half of the people who take them suffer adverse effects such as drowsiness, respiratory depression, and gastrointestinal symptoms such as constipation, reflux, heartburn, cramping, nausea, and vomiting. Moreover, other adverse effects of opioids include a paradoxical increase in pain sensitivity, reduced testosterone levels, and erectile dysfunction. . . . The side effects often outweigh the benefits."¹⁷²

Despite the above, more people are being prescribed these drugs -- a trend the author attributes to extensive marketing.¹⁷³

My Way or the Highway

Imagine a marriage in which one partner's stance is, "I'll tell you what to do, and if you disagree with me about anything, you can leave. We'll get a divorce." Does that sound like a relationship that would encourage you to engage, ask questions, and explore the pros and cons of different choices?

Now consider how one doctor described the relationship between doctors and patients: "The physician-patient compact basically states that a doctor will care for a patient in exchange for compensation and that the patient will heed the doctor's advice. Patients who disagree with their physicians . . . are free to go elsewhere."¹⁷⁴ Does *that* sound like a relationship that would encourage you to engage, ask questions, and explore the pros and cons of different choices?

Health care professionals and policy makers want you to take more responsibility for your health. Part of what they often mean is that they want you to do as you are told. In other words, you are expected to comply with orders given by someone who may focus more on ordering treatments than on what happens to you as a result.

Whose Choice?

Doctors get incensed whenever insurance companies make decisions about what care they can deliver (or, to be more precise, what care the insurance company will pay for). That's understandable; none of us likes to have someone breathing down our neck, second-guessing everything we do. Doctors want to rely on their judgment and make the decisions.

Two issues with that stance are worth noting. The first issue is that only about 20-25% of treatments actually have enough facts backing them up to allow one to say for sure whether the

treatment genuinely helps.¹⁷⁵ “Treatments are based largely on rules and traditions, not scientific evidence.”¹⁷⁶

The second issue is that choices are not always clear-cut. As with everything that you purchase, each option may have some features you really like that other options don't have -- and each option may have its own drawbacks. That's where values and priorities come in. The question is *whose*.

For example, if you ask surgeons if you should have surgery, it's not terribly surprising that they say yes a large percentage of the time. Performing surgery is what they do. That doesn't mean that surgery is necessarily the best choice for you. Researchers at Dartmouth did some very clever studies which showed that it is usually the *doctor's* values and priorities that get applied -- not those of the person who has to live with the results.¹⁷⁷

When science shows that the outcomes of two treatments are similar, it would make sense for people to be told the pros and cons of each option and then to decide which one to have, based on their own sense of priorities.¹⁷⁸ However, the patients' preferences often do not guide the decisions in these cases.

When individuals have complete information, they make choices that are very different from those that doctors make.¹⁷⁹ They choose less invasive, less aggressive treatments as much as *60% more often* than do people who aren't given that information and who instead follow their doctors' lead.¹⁸⁰

Here is an example of what happens when people have information about outcomes. Medicare commissioned a study to decide whether to pay for “lung volume reduction surgery” for emphysema.¹⁸¹ The idea is that with the diseased part of the lung removed, the remaining part of the lung will work better. Before the study was done, people took it for granted that the surgery was a life-saving miracle. However, here's what the study showed:

- Eight percent of patients died as a result of the surgery.
- Most people who had the surgery didn't survive any longer than the people who didn't have it.
- A higher percentage of people who had the surgery ended up back in the hospital or in a nursing home in the months following the surgery, compared to similar patients who didn't have the surgery.
- A small group of people did live longer.¹⁸²

Because the lung reduction surgery did help a small subset of the population, Medicare decided to publicize the study and pay for the surgery. The economists were frantic. They thought that “tens of thousands”¹⁸³ of people would go under the knife, at \$50,000 each. They thought this treatment would break the bank. What actually happened? In the first 21 months only 458 people had the surgery.¹⁸⁴

From *Killer Cure: Why health care is the second leading cause of death in America and how to ensure that it's not yours* by Elizabeth L. Bewley. Downloaded from www.killercure.net.

The barriers to adopting patient aids for decision-making (such as charts comparing options) lie largely with doctors. For instance, one study notes that one barrier is the need to prove to practitioners that such aids will help them by “saving time, avoiding repetition [having to explain things to patients], not requiring extra calls from patients, potentially decreasing liability, and potentially reducing wait-list pressures.”¹⁸⁵

Page | 12

Notice that that nowhere in the list of benefits doctors seek is assurance that they are providing the treatment that best meets patients' priorities and needs.

NOTES

¹³⁸ Surescripts website, <http://www.surescripts.com/Surescripts/e-prescribing-facts.aspx#market>, 27 February 2009 (link no longer functional). The following data was reported:

- 4,416,285,490 -- Total Prescriptions Written
- 883,257,098 -- Unfilled
- 3,533,028,392 -- Total Dispensed
- The U.S. spent \$270 billion on prescription drugs in 2007.

¹³⁹ Ibid. 4,416,285,490 prescriptions written divided by 300 million people = 14.72/person.

¹⁴⁰ "Taking Medicine Is an Important Part of Staying Healthy," *Aetna Member Essentials*, May 2009. This view is representative of the industry.

On a related note, there are entire businesses dedicated to helping pharmaceutical companies drive compliance. The website of one of these, Consumer Health Information Corporation, headlines its "Patient Compliance Strategies" section with the following comment: "The real measure of your product's success is how well you have convinced the patient to take your product correctly over the long term." In context, "correctly" appears to mean "takes all doses prescribed." Note that there is no reference to the idea that success might be measured in terms of improving patients' health.

¹⁴¹ Sundeep Khosla, "Increasing Options for the Treatment of Osteoporosis," *New England Journal of Medicine*, 12 August 2009.

¹⁴² Sandra G. Boodman, "Are Doctors To Blame?" *Washington Post*, 27 May 2008.

¹⁴³ "Problems with Medical Decision-Making," *Foundation for Informed Medical Decision Making*, http://www.informedmedicaldecisions.org/problems_with_medical_decision_making.html, downloaded 17 October 2009.

¹⁴⁴ Derjung M. Tarn, John Heritage, Debora A. Paterniti, Ron D. Hays, Richard L. Kravitz, and Neil S. Wenger, "Physician Communication When Prescribing New Medications," *Archives of Internal Medicine*, 25 September 2006.

¹⁴⁵ This result is calculated by multiplying the six percentages listed. For those of you who are not statistics wizards, think of it this way: assume doctors tell 50 people out of 100 one fact. Then assume that you stand the same 100 people up in a row and the doctors tell a randomly chosen 50 of them a second fact. There's no reason to believe that the 50 people who heard the second fact are the same 50 people who heard the first fact. So it's logical to believe that the number of people who heard both facts is a lot less than 50. Mathematicians have figured out that it's likely to be 25 people who heard both facts. Another 25 heard neither fact, another 25 heard only the first fact, and another 25 heard only the second fact. When six facts are involved, it's clear that the number of people who hear all six facts is going to be very low unless the percent who hear each fact is very high -- say, 95% or so. Even then, fewer than 75% of the people would have heard all six.

¹⁴⁶ Duff Wilson, "Harvard Medical School in Ethics Quandary," *New York Times*, 04 March 2009.

¹⁴⁷ Ibid.

One visible part of the medical school's response was a variation of "shoot the messenger" which one might term "muzzle the messenger." Shortly after the above *New York Times* article appeared, the school created a policy prohibiting any contact between students and the press that didn't go through the dean and the school's Public Affairs department, which deals with the press. After the entirely predictable outcry that this policy provoked, the school authorities appear to be recanting -- in any event they promise to "revise" it. See Duff Wilson, "Harvard Backs Off Media Policy," *New York Times*, 02 September 2009.

¹⁴⁸ Gardiner Harris, "Prosecutors Plan Crackdown on Doctors Who Accept Kickbacks," *New York Times*, 04 March 2009.

¹⁴⁹ Ibid.

¹⁵⁰ Gary Ahlquist, Charles Beever, Rick Edmunds, and David G. Knott, "Consumer and Physician Readiness for a Retail Healthcare Market: Changing the Basis of Competition," *Booz Allen Hamilton Consumerism Survey Report*, 2007.

¹⁵¹ Anne Harding, "Docs Often Write Off Patient Side Effect Concerns," *Reuters Health*, 28 August 2007.

¹⁵² Ibid.

¹⁵³ Dr. Wall is an alias.

¹⁵⁴ Susan Edgman-Levitan, "NQF 2008 Implementation Conference on Care Coordination: Communications," The John D. Stoeckle Center for Primary Care Innovation, March 2008.

Early underlying research: Clarence H. Braddock, III, Stephan D. Fihn, Wendy Levinson, Albert R. Jonsen, and Robert A. Pearlman, "How Doctors and Patients Discuss Routine Clinical Decisions," *Journal of General Internal Medicine*, June 1997. This research suggests that patients can be considered informed decision-makers if six characteristics are present in their conversation with the doctor: discussion of the decision to be made, discussion of alternatives, discussion of benefits and risks, discussion of uncertainties, assessing patients' understanding, and asking patients to express a preference. The study concludes that discussions about clinical decisions, on average, include only 1.23 of these. "Discussion of risks and benefits was less frequent (9%). The least frequently included element was discussion of the patient's degree of understanding (2%)." It does not appear that this picture has changed radically since this study was done.

¹⁵⁵ This estimate is a synthesis of discussions with a variety of health care industry researchers. The most common views were that on average 40-50% of the time, any given individual is not helped by a given treatment.

¹⁵⁶ "Lyrica Significantly Reduced Pain and Helped Patients Manage the Symptoms of Fibromyalgia, Data Show," *Pfizer press release*, 01 May 2007. "Significantly more patients treated with Lyrica reduced their pain by 50 percent or more compared with placebo. Of those patients taking 600mg of Lyrica a day, 30 percent said their pain was cut in half or better; 27 percent of those taking 450mg a day and 24 percent of those taking 300mg also reported this level of pain relief. Of those taking placebo, 15 percent reported pain reduction of 50 percent or greater."

¹⁵⁷ Lee Bowman, "New Diabetes Treatment Helped Prevent the Disease in Studies," *Topeka Capital-Journal*, 18 September 2006.

¹⁵⁸ John Carey, "Do Cholesterol Drugs Do Any Good?" *Business Week*, 17 January 2008.

¹⁵⁹ "Artificial Lumbar Disc Replacement," Blue Cross Blue Shield Technology Evaluation Center, 2007, <http://www.bcbs.com/betterknowledge/tec/press/artificial-lumbar-disc.html>, downloaded 24 June 2007.

¹⁶⁰ Harry N. Herkowitz, "Total Disc Replacement with the CHARITE Artificial Disc Was as Effective as Lumbar Interbody Fusion," *Journal of Bone & Joint Surgery*, 01 May 2006. "Clinical success was defined as a $\geq 25\%$ improvement in ODI [Oswestry Disability Index] score at 24 months [after surgery], no device failure, no major complications, and no neurological deterioration. . . . Clinical success was 64% in the Charite group."

¹⁶¹ John Carey, with Amy Barrett, "Is Heart Surgery Worth It?" *Business Week*, 18 July 2005.

¹⁶² John Carey, "Do Cholesterol Drugs Do Any Good?" *Business Week*, 17 January 2008. "The dramatic 36% figure has an asterisk. Read the smaller type. It says: 'That means in a large clinical study, 3% of patients taking a sugar pill or placebo had a heart attack compared to 2% of patients taking Lipitor.' Now do some simple math. The numbers in that sentence mean that for every 100 people in the trial, which lasted 3 1/3 years, three people on placebos and two people on Lipitor had heart attacks. The difference credited to the drug? One fewer heart attack per 100 people. So to spare one person a heart attack, 100 people had to take Lipitor for more than three years. The other 99 got no measurable benefit."

Researchers use a statistic called Number Needed to Treat (NNT) to clarify how many people have to take a drug for one person to benefit. In the previous example, the NNT is 100 -- one hundred people had to take the drug for one person to benefit.

"For many other drugs, the NNTs are large. Take Avandia, GlaxoSmithKline's drug for preventing the deadly progression of diabetes. The blockbuster, with \$2.6 billion in U.S. sales in 2006, made headlines in 2007 when an analysis of clinical trial data showed it increased the risk of heart attacks. The largely untold story: There's little evidence the drug actually helps patients. Yes, Avandia is very good at lowering blood sugar, just as statins lower cholesterol levels. But that doesn't translate into preventing the dire consequences of diabetes, including heart disease, strokes, and kidney failure. Clinical trials 'failed to find a significant reduction in cardiovascular events even with excellent glucose control,' wrote Dr. Clifford J. Rosen, chair of the Food & Drug Administration committee that evaluated Avandia, in a recent commentary in *The New England Journal of Medicine*. 'Avandia is almost the poster child for everything wrong with our system,' says UCLA's Hoffman. 'Its NNT is close to infinite.'"

NNT is explained further on a website, www.nntonline.net, run by Dr. Chris Cates. Dr. Cates has created a computer program to help doctors understand how to translate research results into more meaningful information to help them better practice medicine.

On a related note, see Tara Parker-Pope, "A Call for Caution in the Rush to Statins," *New York Times*, 18 November 2008. She summarizes a study: "Only 1.8% of the subjects who took a placebo had a major cardiovascular problem during the study period. Among statin users, 0.9 percent did. In other words, the absolute risk of a serious cardiovascular problem (as opposed to the relative risk) was reduced by less than one percentage point."

¹⁶³ John Carey, "Do Cholesterol Drugs Do Any Good?" *Business Week*, 17 January 2008.

¹⁶⁴ Leila Abboud, "Largest Ever Studies On Drugs for Depression, Schizophrenia Could Transform Treatment," *Wall Street Journal*, 27 July 2005.

¹⁶⁵ "Prescription Drugs That Cause Weight Gain," *Johns Hopkins Health Alerts*, 23 January 2007, www.johnshopkinshealthalerts.com.

¹⁶⁶ Charlene Laino, "Is Your Medicine Cabinet Making You Fat?" *WebMD Weight Loss Clinic*, 06 July 2007, downloaded from www.medicinenet.com.

¹⁶⁷ Mary Duenwald, "Is Your Medicine Cabinet Making You Fat?" *New York Times*, 16 August 2005. Although two articles referenced in this section have the same headline, they are unrelated.

¹⁶⁸ Kathleen Zelman, "Lose Weight, Gain Tons of Benefits," *webmd.com*, 23 June 2006.

See also "Improving Your Health," U.S. Department of Health and Human Services, July 2006. "Losing 5 to 10 percent of your body weight can help improve your health."

¹⁶⁹ Mary Duenwald, "Is Your Medicine Cabinet Making You Fat?" *New York Times*, 16 August 2005.

¹⁷⁰ *Ibid.*

¹⁷¹ "Kaiser Health Tracking Poll," Kaiser Family Foundation, February 2009. When asked, "Do you currently take any prescription medicine on a daily basis, or not?" 49% said yes, 50% said no, and 1% declined to answer or did not know.

¹⁷² Orly Avitzur, "Be Wary of Narcotics to Treat Back Pain," *Consumer Reports*, May 2009.

¹⁷³ *Ibid.*

¹⁷⁴ Rahul K. Parikh, "Showing the Patient the Door, Permanently," *New York Times*, 10 June 2008.

¹⁷⁵ Sean R. Tunis, "Reflections of Science, Judgment, and Value in Evidence-Based Decision-Making: A Conversation with David Eddy," *Health Affairs*, 19 June 2007.

¹⁷⁶ John Carey, "Medical Guesswork," *Business Week*, 29 May 2006.

¹⁷⁷ *Ibid.*

¹⁷⁸ "Supply-Sensitive Care," A Dartmouth Atlas Project Topic Brief, *The Dartmouth Atlas of Health Care*, 15 January 2007. "There is unwarranted variation in the practice of medicine and the use of medical resources in the United States. There is underuse of effective care, misuse of preference-sensitive care, and overuse of supply-sensitive care."

"Effective care" tends to refer to low-tech prevention or maintenance protocols, such as blood sugar screening or having heart attack patients take aspirin to prevent a second heart attack. "Preference-sensitive care" refers to situations in which several viable treatment choices are available, and the decision should be the patient's, but often the doctor essentially makes a choice that is inconsistent with the patient's values and priorities. Health care policy experts term this discrepancy "misuse" of care. "Supply-sensitive care" refers to care for which the determining factor in the equation is not how sick the patient is nor how well they are likely to do after surgery, but how many specialists there are per 1000 patients in the geographic area.

¹⁷⁹ Ibid.

¹⁸⁰ Ibid.

See also, John Carey, "Smarter Patients, Cheaper Care?" *Business Week*, 22 June 2009. The article is subtitled, "Better-informed medical decisions could cut billions in health-care costs as patients opt for cheaper treatments."

See also Laura Landro, "Weighty Choices, in Patients' Hands," *Wall Street Journal*, 04 August 2009: "Studies show that when patients understand their choices and share in the decision-making process with their doctors, they tend to choose less-invasive and less-expensive treatments than they would have otherwise received."

¹⁸¹ Gina Kolata, "Medicare Says It Will Pay, but Patients Say 'No Thanks,'" *New York Times*, 03 March 2006.

¹⁸² "National Emphysema Treatment Trial (NETT): Evaluation of Lung Volume Reduction Surgery for Emphysema," Department of Health and Human Services, National Institutes of Health, National Heart, Lung, and Blood Institute, <http://www.nhlbi.nih.gov/health/prof/lung/nett/lvrsweb.htm#results>, 20 May 2003.

¹⁸³ Gina Kolata, "Medicare Says It Will Pay, but Patients Say 'No Thanks,'" *New York Times*, 03 March 2006.

¹⁸⁴ Ibid.

¹⁸⁵ Annette M. O'Connor, Hilary A. Llewellyn-Thomas, and Ann Barry Flood, "Modifying Unwarranted Variations in Health Care: Shared Decision Making Using Patient Decision Aids," *Health Affairs*, 07 October 2004.