

Kai Ryssdal: This week the Institute of Medicine released a study on the follow-up care for cancer patients after they finish treatment. The main finding was that many of the ten million cancer survivors in the United States don't get the care they need post-disease. On this week's Money Matters, our regular look at how to improve your bottom line, we talk to a cancer survivor. Stephen Schneider is a professor at Stanford University, and his new book, *Patient From Hell* relates his cancer experience and how he navigated the health care system. Professor Schneider, welcome to the program.

Stephen Schneider: Thanks Kai, glad to be here.

KR: Tell us about your disease a little bit.

SHS: I have mantle cell lymphoma. It's a non-Hodgkin's B-cell, part of my immune system, my B-cells reproduce out of control so therefore we've got to prevent them from doing that by basically getting rid of them and I went through a lot of treatments to try to do that and so far so good.

KR: And, like any other patient, you went to see your doctor once you discovered this lump under your arm that led you to the diagnosis of the disease, but in a whole lot of ways, you're not like any other patient. First of all you have a PhD in plasma physics for crying out loud.

SHS: I was as I jokingly call my book title the patient from hell because I did question everything but I was just very fortunate at Stanford I had, like me, a professor for a doctor. As busy as she was, in the end she was willing to listen to some logic and we made changes to the protocol that are very difficult to do in these relatively high-bound institutions that the medical system in the US is.

KR: You know it's interesting you said at one point in this book, somebody said you know this is extremely rare and you know 14 people on the planet have it or whatever and you said oh great I've got a research disease.

SHS: Yeah you're right I said the gods of irony got even with me. I study climate change there's no such thing as a clinical trial for climate. In other words, how do we know what the likelihood is, it's gonna be one degree or five degrees warmer in 2100. Well we can't, till 2100 rolls around, so what we do is we make educated guesses based on our understanding of how the processes in nature work and then we make extrapolations forward; it's the best we can do. And, medicine hates to do that. And I said you gotta do that, because with a research disease we just don't have enough data to have very very good answers, so let's innovate by figuring out the process and we worked with the doctors we spent a lot of time on the web and eventually they were willing to overwrite protocols and do things that I'm sure caused them some pain, trying to deal with the HMOs and the hospital management, who want to do what I call medicine by the numbers; one size fits all, that just wasn't gonna work for this kind of disease.

KR: You write that there is a lot of decision analysis and cost-benefit analysis and very basic stuff that you deal with in other kinds of science on a daily basis. It's not there in medicine today.

SHS: Well it's there, it's just not there nearly enough. Let me give you an example that everybody can relate to. We all know somebody who has cancer. So I asked, if we don't do any treatment after the initial treatment, in my case it was bone marrow transplant, chemo and so forth, we don't do it, what we call maintenance therapy, that's continuous prophylactic re-intervention to just prevent anything from happening; that's what I wanted. They said: we don't do that! I said well why don't you do that? Well because there's a rule in medicine to do no harm. Not every patient is gonna get their cancer back and these drugs are dangerous and they have side-effects so we don't want to risk that on the patient group that wouldn't get their cancer back. I said so let's do decision-analysis, let's run the numbers. How many people do you think are going to lose remission with my disease or a typical cancer and the answer varies all over the place but a typical number is like half. I said ok how many people, once they lose remission, are going to be able to be saved? How many are going to get back? Well, at most, half. That means I have a 50% chance that I'm going to get it back; 50% chance it's not going to work. So now, tell me, if you had a hundred patients, how many of them are going to be killed by the drugs? One or two. I said it's a no-brainer! You got 25 people who are gonna die almost for certain if we do nothing and only 1 or 2 if you intervene; it's obvious you have to change your paradigm away from this "do no harm," you're doing egregious harm by not applying decision analysis. My doc said, your logic is right, and we changed the protocol.

KR: And you're still talking to your doctor and your doctor's still talking to you?

SHS: My doctor, Sandra Horning, is the president of ASCO, that's the American Society of Clinical Oncologists, and she's told me that she does get phone calls and emails and doctors like why did you work with this guy now all my patients want the same thing! And you know what, she smiled and said, you know what, it's working for you; let's hope it works for them.

KR: You're reasonably well off, you're well-educated, er, not all patients out there are.

SHS: Well, in fact the situation is pretty dire for the vast bulk of people in the world. In the United States something like 40% of people don't have insurance and these treatments are expensive, and if they had this disease they'd be in pretty bad shape, and they would get, *at best*, standard protocols, if they checked into a hospital in time. So we have a problem, and what I'm trying to do is not pretend that being the patient from hell and getting them to improve protocols is going to solve the public health problems in the world, but I think if the best institutions improve by individualizing dealing with patient care on a more individual basis, it'll trickle down and hopefully, eventually work its way to people who are less fortunate, but that will not be solved without social change in which we make health care a human right and we have a long way to go politically before that, I think, needed step occurs.

KR: Stephen Schneider is a professor of biological sciences at Stanford University. His book is called *The Patient From Hell*. Professor Schneider thanks so much.

SHS: Thanks very much Kai.

KR: You can find a link to Professor Schneider's book on our website, it's marketplace.org. This is Marketplace Money, from American Public Media.