

Crowdsourcing Our Health

by Brenda Denzler

Have you ever noticed the way doctors roll their eyes when you tell them you've been on the internet to find out more about your diagnosis—or in the absence of a diagnosis, your symptoms? And if you tell them that you joined an on-line support group for your particular health concern, have you noticed how quickly they'll tell you to stay away from those things? One of my doctors recently found out that for a pretty modest fee I could get an online company to authorize a blood test to check my kidney function.

"Without a doctor's order?" he asked, incredulous.

"Yup," I said. "It's just a creatinine test. No big deal."

He shook his head slightly and said, "It's a brave new world out there."

And indeed, it is.

What the invention of the printing press did for religion 500 years ago, the growth of the Internet started doing for medicine 50 years ago. In centuries gone by, easier access to books of all kinds meant that the priestly monopoly on access to sacred texts disappeared and with it, their privileged knowledge and interpretations of the writings that claimed to point the way to life eternal. How to achieve salvation became a matter of much more lively debate among the ordinary faithful, and there was, in the end, little that the priestly caste could do about it except decry this massive falling away from the faith of which they had once been the cognoscenti, the sole arbiters.

In the early 20th century the rise of modern medical schools created another privileged caste—the physician. While there had always been doctors and "wise women" dispensing better and worse remedies within their little orbits of influence, medical schools began to churn out doctors in greater numbers and supported the professionalization of the discipline.

Along with an upgrade in the quality of its practitioners came a refinement in the quality of medical knowledge and an explosion in its quantity. All of this became codified in weighty tomes like Gray's Anatomy or the Physician's

Desk Reference—opaque texts that spoke to the new cognoscenti but were pretty much inaccessible or impenetrable to the masses. The new "priestly" caste, like their forebears, had near-exclusive access to the knowledge pointing the way to life and death (at least, of the body), and they received much of the same awe and respect that their religious predecessors had enjoyed.

With the advent of the internet, however, this interlude of veneration has begun to fade. Medical knowledge has become democratized like never before. Hard-to-find medical textbooks and medical journal articles are just a click away. Obscure technical language can be parsed with another click of the mouse. Every medical institution or disease-focused interest group worth its salt has a website overflowing with much of the same information presented in simpler language.

Not only has much formerly privileged medical information become commonly accessible, more questionable health information is just as available. For a modest cost, anyone can put up a website to promote their particular take on any given medical issue and try to generate followers. The digital age does not take sides in questions about the health of the body, just as the printing press did not take sides in questions about the health of the soul.

One of the most powerful sources of health information today, however, lies not in the classic medical texts, not in the overwhelming numbers of medical journal articles, and not in the myriads of health information websites, whether good or bad.

One of the most powerful sources of health information today is other patients with the same health problem. Thanks to the internet, we are connected and communicating as never before, with the result that we are increasingly crowdsourcing our health. The experiences of others who have the same symptoms or the same diagnosis can go a long way toward pointing us toward our own answers.

"The nodule over your larynx seems to have cancerous cells in it, but we don't know what kind." My young ENT surgeon was relaying the results of a fine needle aspiration we'd

done on a lump I'd discovered on my throat. "Cytology says the thyroid gland itself looks alright, but we probably just didn't hit the site of a malignancy when we aspirated the gland and the cancerous cells in the nodule really did come from the thyroid. Both of them need to come out."

"OK," I said thoughtfully. Then I continued, my voice a bit huskier as I suppressed tears. "I don't do well with surgery and being knocked out and all that. It's really, really terrifying for me."

"We don't have to schedule surgery today," he said, sitting down and taking my hand to calm me. "You can think about this for a few days. Alternatively, we could do another fine needle aspiration to try to get better samples, and re-evaluate the situation."

"Ugh!" I said, grimacing. "The first one hurt like hades! I'm not a big fan of trying that again!"

"I understand," he said. "Why don't you think about this, and let's talk again next week?"

When I got home, I shook off my dazed stupor and began doing my homework. Thyroid cancer...what are the signs and symptoms? What is the treatment? What's the prognosis? Then I'd stop and fall into a stunned reverie. "I can't believe this is happening again," I thought. "I can't believe I've got cancer again."

As I looked around for information, I wanted more. I wanted to know not just the formal reality of thyroid cancer—the kind of stuff that gets written up in academic papers, posted on websites, and spouted by doctors—I wanted to know the personal reality of it. I found a local thyroid cancer support group and one on Facebook. I signed up for both. I also sought a second medical opinion.

"So don't let them take out the thyroid yet," said the second doctor. "Let them take out the lump over your larynx. They should be able to do that without sedation—just a local anesthetic. Then they'll be able to analyze the whole lump. If it shows definite involvement of the gland, then you have another decision to make."

"You know," said the support groups,

"given your symptoms, it might be an autoimmune condition called Hashimoto's thyroiditis and not cancer at all. Or it could be both. You need to get your TPO and TGAb tested, just to be sure."

With the approval of my surgeon, I scheduled the surgery the second doctor had suggested. Four days later, I had the blood tests the support groups had suggested. In the end, not only did the pathology report on the lump reassure me that I did not have thyroid cancer after all, but it confirmed the diagnostic information that had already been suggested to me by the support group and was found by the bloodwork: it's Hashi's!

My doctors can roll their eyes and caution me all they want, but I will continue to read up on health issues using all the resources of the internet. I will rely on the most reputable sites and the most highly vetted information, but will not be afraid to consider the information on sites without a formal medical imprimatur. I will continue to draw upon the collective wisdom of others with my symptoms and diagnoses. I will patronize internet-based health testing labs if necessary.

In short, I will continue to crowdsource my health, because it IS a brave new world out here.

Brenda Denzler was diagnosed with inflammatory breast cancer in 2009. She became a cancer survivor on the very day she was diagnosed.

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