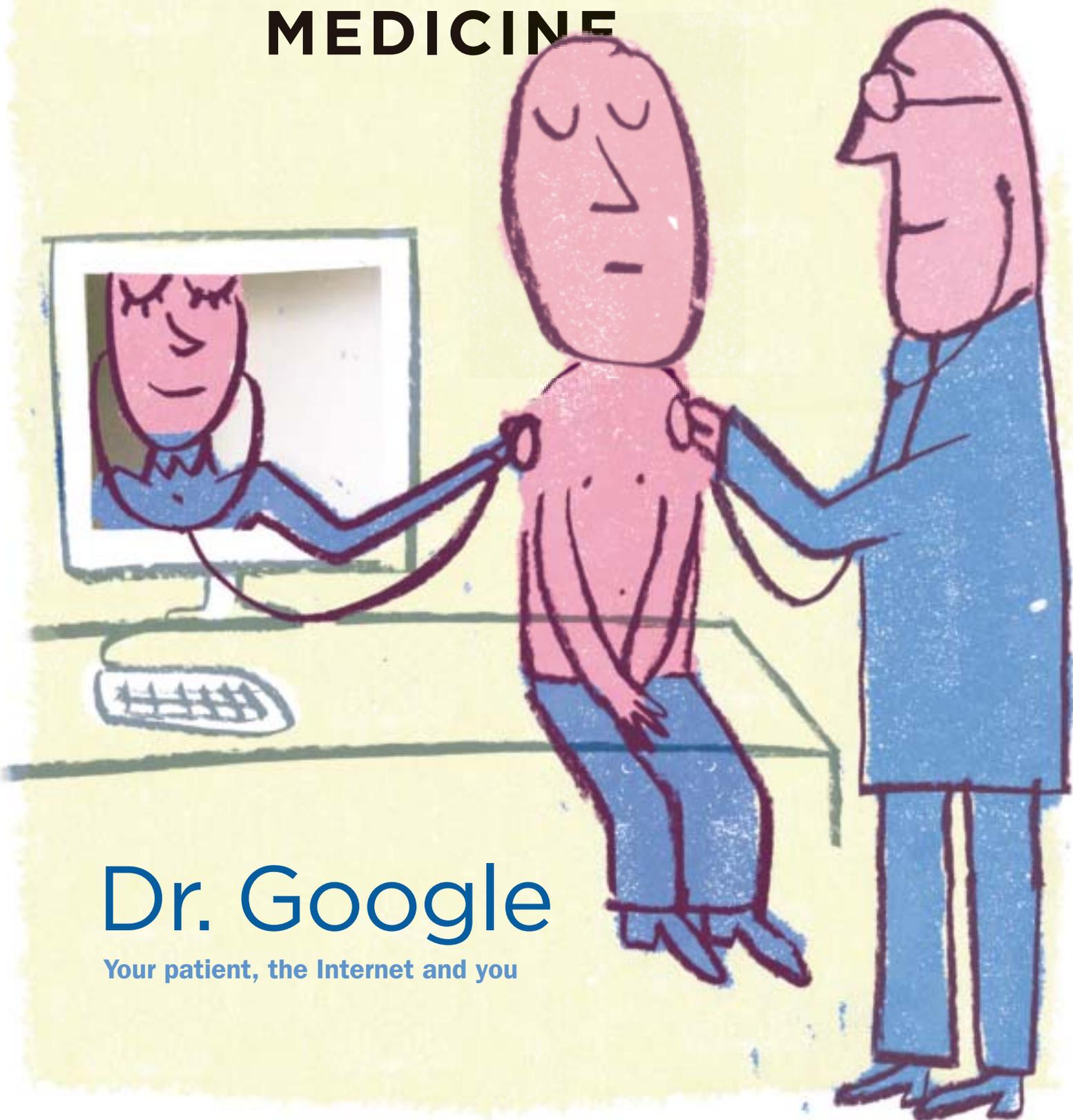


Tufts

MEDICINE



Dr. Google

Your patient, the Internet and you

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What your patients are doing
online, and why you should care

DR. GOOGLE

BY LISA NEAL GUALTIERI, PH.D.,
AND JANEY PRATT, '93

PICK YOUR WORST NEW PATIENT NIGHTMARE.

A patient tells you what tests and treatments they need for their Internet-inspired diagnosis, and when you ask about symptoms, it becomes apparent that they are mistaken. Unfortunately, in cases like this, you find yourself arguing with your patient about how to do your job. Or alternately, let's say a new patient who searched your name online and read a tirade by a former patient whose lawsuit against you was thrown out quizzes you about the dismissed case. The latter is upsetting, and the former is, well, upsetting, too.

The medical profession has changed in recent years with more paperwork, more physicians seeking a "normal" lifestyle (such as working part-time) and fewer medical school graduates. Physician referral patterns and consultation have also changed, with patients not only researching the choice of a doctor online but also digging into related matters like which hospital is best and which tests should be ordered. Sometimes this easy access to information makes your job as a physician harder, such as when a patient hands you an inch-thick ream of print-outs and wants your feedback—or, worse yet, starts barraging you with questions about articles they have read on random websites.

But like a lot of things we complain about, patients' frequent use of the Internet is not all bad. "The worst of the Internet," says Harris Berman, vice dean of academic and clinical affairs at the medical school, "is when online medical research hijacks an office visit or prevents a patient from getting care. The best is when it helps a patient manage a disease better. The biggest challenge for doctors is to steer their patients to advantageous uses of the Internet."

ILLUSTRATIONS BY SERGE BLOCH

EIGHTY-FOUR PERCENT of American adult Internet users, or about 160 million people, looked for health or medical information online in 2007.

It is likely that your patients are going online, whether they tell you or not. Eighty-four percent of American adult Internet users, or about 160 million people, looked for health or medical information online in 2007, up from 80 percent in 2006, according to a recent Harris poll. *Online Health Search 2006*, from the Pew Internet & American Life Project, similarly reports that 80 percent of Internet users in the U.S. have researched health and medical advice online, based on telephone interviews conducted with 2,928 adults by Princeton Survey Research Associates.

Some of the findings were predictable. A search engine is the most popular starting point, used by 66 percent of health-care seekers, according to Pew. Three quarters of people do not consistently examine the quality indicators of information they find online, checking the “source and date ‘only sometimes,’ ‘hardly ever’ or ‘never.’” Eighteen percent say they were confused by the information they found online, and 10 percent felt frightened by the serious or graphic nature of the information, making it more concerning that only a third of these people “later talked with a doctor or other health professional about the information they found online.”

ENDLESS POSSIBILITIES

Between poor information and undeveloped health literacy skills, many patients believe that pounds can literally melt away and that cures exist for incurable diseases. An example of this naiveté occurs with Alzheimer’s disease, for which a recent YouTube video that has been viewed thousands of times depicts a treatment that claims to reverse the effects of the disease. Berman recounts how a friend’s wife told him that her online search found a cure for her husband’s ALS in Germany and was going to take him there until he convinced her that “if such a cure existed, doctors here would know about and use it, too.”

When your patients go online, they can be swayed by almost anything they come across, to the point of abandoning common sense. Here is where you can play an important corrective role. As patients talk to you about what they have found, their impressions can be balanced by your informed medical opinion. But that’s assuming such a conversation occurs in the first place. Some patients don’t feel comfortable talking to doctors about their Internet findings, as the Pew data show, and some doctors discourage their patients from broaching the subject, which can lead to an even more passionate use of the Internet on the part of patients.

A patient we’ll call Julie, a researcher in a Boston hospital, experienced this. She tried to talk to her doctor about some information she came across online on the subject of uterine cancer, “but all he said was, ‘We cannot know until we do the biopsy,’ which may have been medically true but didn’t calm my fears,” Julie relates. “My anxiety led me to search obsessively. Plumbing the depths of the Internet is far more responsive to my needs since I can openly search on any topic that I can think of related to my concern.”

It’s easy for patients to get in over their heads. Looking symptoms up online can be confusing—and frightening—for someone who lacks medical expertise, because there are seemingly endless possibilities to consider. The term “cyberchondria” describes people who believe they have a disease that they read about online. “Patients look up what they think they might have, see it could be one of a few things, of which some are terrible, while others are fine,” notes Lisa Possick Arbesfeld, ’88, a Lexington, Mass., dermatologist. “They then become scared for no reason at all while waiting for their appointment.” While there may not be a cure for cyberchondria, the best treatment is a trusted physician making a correct diagnosis.

Ylisabyth (Libby) Bradshaw, an assistant professor in the department of public health

and family medicine, recounts how a patient looked up symptoms online and arrived at her office frantic over the possibility that he had the “flesh-eating disease” (necrotizing fasciitis). An examination found he did not. This may have been an example of too much data frightening the patient, but small bits of highly prejudicial information can be harmful as well.

Toby Nathan, a Bedford, Mass., pediatrician, has seen this happen more than once. Nathan is particularly concerned about fears about immunization that parents encounter online and that lead them, against her recommendation, not to immunize their children. “Some of these children get the very diseases they could have been protected against,” she says. Of course, as Nathan points out, “There have always been sources of misleading information before the Internet, although they were not so easily available or as compelling.”

In some cases the Internet can function as a handy diagnostic tool, leading patients to seek out essential medical care more promptly than they might otherwise. Saul, a Montreal professor, had a cold for several days but became very concerned when he noticed that his leg was swelling up and hurting. Saul used a symptom checker he found on the Internet that advised him to seek immediate medical attention. Saul went to see his doctor immediately, despite his fears that his doctor would chastise him for being overweight. The doctor diagnosed and hospitalized Saul with cellulitis and told him that he was lucky he hadn’t waited any longer to be treated.

ONE MORE TOOL

For most of us, the Internet has become a new variable to factor into the doctor/patient relationship. In addition to what occurs during a consultation, physicians need to think about what happens afterwards. Many patients go online following an office visit to

verify a diagnosis, broaden their understanding of their medical condition or join an online support group. Some physicians provide guidance about which sites to visit, which can be helpful to patients.

Bruce Auerbach, president of the Massachusetts Medical Society, finds this physician guidance the best way to deal with the “great variability of information on the Internet. To ensure patients use credible, reliable sites, send them to trusted sources, including medical specialty societies, state associations and recognized organizations such as the American Heart Association and the American Diabetes Association,” he suggests.

Many physicians go online themselves to look up a medication dose or side effects, to find a physician to refer their patient to or to learn more about a disease. This has the further benefit of helping them to understand just what their patients are seeing online. Diane Aronson is a past president of the Road Back Foundation, where she helped develop a popular website devoted to rheumatic diseases. “Physicians can learn from websites,” she observes, “especially from the discussion forums where patients talk about their experiences with diseases and treatments. Physician use of websites within their medical specialty can validate concerns, draw on both the physician and patient experiences and lead to a successful mutual approach to treatment.”

Online resources can help your patients become better educated about medical topics, more confident and comfortable with you and more compliant with treatment. As Anthony Schlaff, director of the M.P.H. program at the medical school, notes, “At its best, the Internet is one more tool in the partnership between a physician and patient.” Auerbach, the Massachusetts Medical Society president, couldn’t agree more. “Given that patients are going online,” he says, “the best thing to do is engage them as partners in care.” TM

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HOW TO DEAL

Based on her own experience, Libby Bradshaw offers the following tips for dealing with Web-savvy patients:

FIRST, figure out what the problem is yourself. “If the patient immediately brings up that they’ve been searching online, I thank them and compliment them for doing all this work,” she says. “Then, I ask them to tell me what’s wrong in their own words—just the facts, no opinions. I try to emphasize we have to consider everything, and that I really want to get to all they’ve looked up and their opinions, but we have to do this part first.”

SECOND, once you have a diagnosis, let the patient talk about his or her Internet research. “Once I have an idea of what their problem is, then I’m willing to look at their search results to see the topics and sources. Often it is overwhelming for patients to do this searching, so I find out what they concluded from their research to identify which part was useful.”

THIRD, respect a patient’s efforts. This reduces fear and builds trust. “If I am respectful about their effort, they are relieved that I could summarize the conflicts in the information, and have more confidence in me since I was clearly ‘up’ on the information they had found and then they trust that I knew what I was saying. Sometimes sophisticated patients have identified useful information that helps in their treatment plan.”