Curbside Consultation

Communicating Risk to Patients Who Get Their Information from the Internet

Commentary by Barry D. Weiss, MD

Department of Family and Community Medicine, University of Arizona College of Medicine, Tucson, Arizona

Case Scenario

A 67-year-old woman came to my clinic with uncontrolled hypertension and stage 3 chronic kidney disease. She told me she had not taken her lisinopril because she read on the internet that taking lisinopril causes lung cancer. I searched online and found the population-based cohort study that appeared to be the source of my patient's concerns. What can physicians do when our patients act on findings from the internet? How do physicians address information that tells us that additional studies and more long-term follow-up are needed when our patients have already decided that the alleged risk outweighs the benefits?

Commentary

This case raises important issues related to communicating with patients, including where and how patients get health information, how reliable the information is, and, above all, how well patients understand risk relating to the information. Regarding these issues, physicians need to know the best way to provide patients with convincing, reliable, and accurate information about risk.

WHERE DO PATIENTS GET HEALTH INFORMATION?

Some studies show high percentages of patients getting information from health professionals[1]; however, national data show otherwise. The annual Health Information National Trends Survey reports that nearly one-half of U.S. adults use the internet as their first source of medical information, whereas only 10% to 15% rely on health care professionals.[2] Perhaps not surprisingly, younger adults are more likely than older adults to seek health information on the internet.[3] Many individuals, particularly the one-third of U.S. adults with limited literacy,[4] are likely to get health information primarily from television, social media, and celebrity webpages,[1] and they are less likely to trust information on government websites.[5,6]

HOW RELIABLE IS THAT INFORMATION?

The internet provides many excellent sources of health information. Physicians regularly use online resources to guide them in the care of patients. However, studies and media reports indicate that members of the public are not always able to distinguish reliable and authoritative health information from unreliable and incorrect information. Individuals tend to believe things that match their own preexisting biases.[7] Fake medical news is common, ranging from the well-known false reports of childhood vaccines causing autism or seizures to reports of statins causing cancer.[8] Patients often make decisions (e.g., not getting their children vaccinated, not taking their prescribed statins) after reading about or hearing this incorrect information. They may even reject conventional cancer therapies and turn instead to ineffective alternative medicine treatments, resulting in substantial increases in cancer-related death rates.[9]

HOW WELL DO PATIENTS UNDERSTAND RISK?

Some information that patients find on the internet is factually correct. For instance, patients taking lisinopril do have increased rates of lung cancer, even after adjusting for smoking status. The increased risk, however, is miniscule. Among patients taking the drug for an average of 6.4 years, the rate of lung cancer was 1.6 per 1,000 people compared with 1.2 per 1,000 people not taking the drug.[10] That is a difference of 0.4 per 1,000 people, meaning the drug may cause cancer in one out of every 2,500 people who take it for more than six years.

Research shows that most patients do not understand these risk statistics. In one notable study, patients attending an asthma clinic were told that a drug carries a 1% chance of causing a side effect. When asked, only 38% of patients knew that 1% means one out of 100.[11]

HOW TO EXPLAIN RISK TO PATIENTS

First, commend patients for taking an interest in their medical care. Then, instead of using percentages and other statistics to explain risk, use the research-supported method of showing the patient images (e.g., icon arrays)[12,13] that can be easily created using websites *(Figure 1*[14]*)*, or provide explanations using event rates (i.e., how many out of how many).[11,15] For example, ask your patient to imagine a basketball arena containing 10,000 people who have high blood pressure. Treating their blood pressure with lisinopril might cause cancer in four out of those 10,000 people, but it will prevent death from heart disease in more than 3,000 of those 10,000 people.[16] The cancer rate associated with patients who take lisinopril is extremely low, whereas the benefit of treating high blood pressure with lisinopril is very high, especially for people with kidney problems, for whom lisinopril is a drug of choice.

Most patients will respond to this kind of explanation, and patient understanding can be confirmed by using the teach-back method—asking patients to explain to you what you have told them.[17] Providing understandable information is only the first step in helping patients understand what they need to know as they contemplate the actions they will take in managing their health. But, it is an important first step.

For the patient in this scenario, commend the patient for paying attention to news about the medication she takes. Explain to her that the information she presented is factually correct, but also explain, using event rates and/or an icon array, the risks of her not taking her medication. You can then use the teach-back method to confirm that she understands what you told her and answer any further questions that she might have.

FIGURE 1

Cancer Cases with Lisinopril   **Heart Disease Deaths Without Lisinopril**
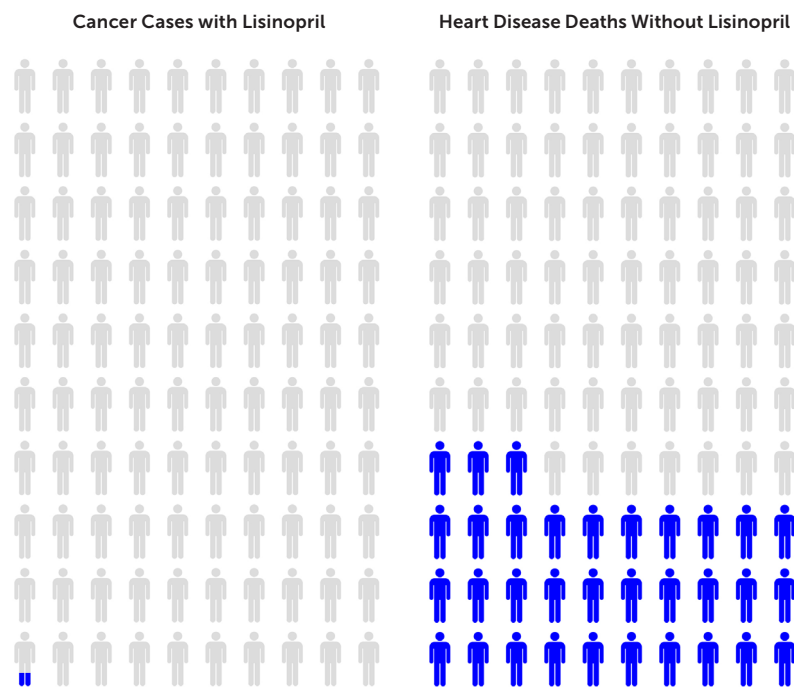
Icon array showing the difference between patients who get cancer while taking lisinopril vs. patients who die from heart disease who did not take prescribed lisinopril.

Images created using iconarray.com. Risk Science Center and Center for Bioethics and Social Sciences in Medicine, University of Michigan. Accessed July 2, 2019. http://www.iconarray.com/

Editor's Note: Dr. Weiss is an Associate Medical Editor for *AFP*.

Address correspondence to Barry D. Weiss, MD, at bdweiss@email.arizona.edu. Reprints are not available from the author.

References

1. Chen X, Hay JL, Waters EA, et al. Health literacy and use and trust in health information. *J Health Commun*. 2018; 23(8):724-734.

2. Jacobs W, Amuta AO, Jeon KC. Health information seeking in the digital age: an analysis of health information seeking behavior among US adults. *Cogent Soc Sci*. 2017; 3(1):1302785.

3. Xie B, Wang M, Feldman R, et al. Internet use frequency and patient-centered care: measuring patient preferences for participation using the health information wants questionnaire. *J Med Internet Res*. 2013;15(7):e132.

4. Kutner M, Greenberg E, Jin Y, et al. The health literacy of America's adults: results from the 2003 National Assessment of Adult Literacy; 2006. Accessed June 27, 2019. https://nces.ed.gov/pubsearch/pubsinfo. asp?pubid=2006483

5. Diviani N, van den Putte B, Giani S, et al. Low health literacy and evaluation of online health information: a systematic review of the literature. *J Med Internet Res*. 2015;17(5): e112.

6. Mackert M, Kahlor L, Tyler D, et al. Designing e-health interventions for low-health-literate culturally diverse parents: addressing the obesity epidemic. *Telemed J E Health*. 2009;15(7):672-677.

7. Meppelink CS, Smit EG, Fransen ML, et al. "I was right about vaccination": confirmation bias and health literacy in online health information seeking. *J Health Commun*. 2019;24(2):129-140.

8. Warraich H. Dr. Google is a liar. December 16, 2018. *The New York Times*. Accessed June 27, 2019. https://www. nytimes.com/2018/12/16/opinion/statin-side-effects-cancer.html

9. Johnson SB, Park HS, Gross CP, et al. Use of alternative medicine for cancer and its impact on survival. *J Natl Cancer Inst*. 2018;110(1):121-124.

10. Hicks BM, Filion KB, Yin H, et al. Angiotensin converting enzyme inhibitors and risk of lung cancer: population based cohort study. *BMJ*. 2018;363:k4209.

11. Apter AJ, Cheng J, Small D, et al. Asthma numeracy skill and health literacy. *J Asthma*. 2006;43(9):705-710.

12. Kim H, Xie B. Health literacy in the eHealth era: a systematic review of the literature. *Patient Educ Couns*. 2017: 100(6):1073-1082.

13. Agency for Healthcare Research and Quality. The SHARE approach—communicating numbers to your patients: a reference guide for health providers. Updated August 2018. Accessed June 27, 2019. https://www. ahrq.gov/professionals/education/curriculum-tools/ shareddecisionmaking/tools/tool-5/index.html

14. Icon array. Risk Science Center and Center for Bioethics and Social Sciences in Medicine, University of Michigan. Accessed July 2, 2019. http://www.iconarray.com/

15. Naik G, Ahmed H, Edward AG. Communicating risk to patients and the public. *Br J Gen Pract*. 2012;62(597): 213-216.

16. Zhou D, Xi B, Zhao M, et al. Uncontrolled hypertension increases risk of all-cause and cardiovascular disease mortality in US adults: the NHANES III linked mortality study. *Sci Rep*. 2018;8(1):9418.

17. Agency for Healthcare Research and Quality. Health literacy universal precautions toolkit, 2nd edition: use the teach-back method: tool #5. February 2015. Accessed July 2, 2019. https://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/ healthlittoolkit2-tool5.html ■