

The Conundrum of Providing Authoritative Online Consumer Health Information: Current Research and Implications for Information Professionals

by Diane M. Neal

How do we know when to trust online health information? Recently, a gynecologist's newspaper column asserted that endometriosis, a disease that primarily affects women, could be diagnosed by an in-office exam and that ovarian cysts could be diagnosed by an ultrasound. These claims are not true; these conditions can only be diagnosed through a surgical procedure. After being informed about the article through social networking outlets, many outraged endometriosis patients – including me – posted comments online in reply to the doctor's article (until the newspaper swiftly closed the comments) and wrote letters to the editor. They published one letter to the editor: mine. Lay endometriosis bloggers announced my letter's publication on their blogs, declaring a small but significant victory in the battle against endometriosis information, and other patients also reveled in the celebration by commenting on the blog posts. Inexperienced in this form of activism, I asked a blogger why she thought my letter was published, but not anybody else's. I thought perhaps they chose it because the column was published in a Canadian newspaper, and I live in Canada. She said she thought it was because I had a PhD, which added authority to my correction. We will never know for sure why the editors chose my letter, but something about it must have captured their attention.

In my role as a library and information science professor, I am currently involved in research related to issues surrounding authority and consumer health information, but this personal experience brought the issue to life for

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me. We can find various interplays of authority in the example. First, the gynecologist (a presumed expert in female diseases) provided incorrect information. Thanks to social networking's ability to link people who suffer from the same health conditions, patients collectively corrected him. Clearly, the traditional model of the patient relying on the expert is not in effect here; instead, the educated patient is correcting the expert. As informed patients, we worried that the doctor's misinformation could further delay undiagnosed endometriosis patients receiving diagnosis and subsequent treatment, especially since the average time from presentation of symptoms to diagnosis is approximately 10 years. From a formal education standpoint, my information science doctorate should be somewhat meaningless for inferring my authority to determine whether the gynecologist was inaccurate, but it might have played a role in publishing my letter.

This experience exemplifies how the traditional lines of authority are blurring and possibly occasionally reversing in the domain of online consumer health information. More examples are created every day as people go online to research medical conditions affecting themselves and their loved ones, compare experiences with fellow patients and caregivers and share their stories. On the other hand, reputable medical professionals have told me that they are frustrated with the mounds of unreliable information that patients read online, incorrectly believing that the latest product or trend can cure their illnesses. Research demonstrates that patients have reliability concerns as well, but their concerns are certainly not stopping them from searching the web. Thanks to the positive, continuing trend toward evidence-based medicine, information professionals certainly can provide people with rigorous empirical research as well as patient information based on research

using tools to which we are accustomed. We are charged with helping people discern these reliable sources from unreliable ones, but it is difficult to do in such an amorphous environment. What happens when the experts proclaim misinformation? And if people are looking for something other than factual advice, mainstream treatment approaches or empirical research, are we prepared to help them meet their information needs?

Authority and Reliability in Research and on the Web

In 1983, Patrick Wilson published *Second Hand Knowledge: An Inquiry into Cognitive Authority*. In this book, he postulated that we learn about the world through our own knowledge, as well as through other people and other sources, but only if we consider the other people and other sources to be authoritative and credible. Several researchers have explored and tested the concept in online and offline contexts. Information behavior researchers have suggested that we largely construct cognitive authority as a community, not on our own. This conjecture seems highly plausible: As social beings, our information practices are frequently influenced by friends, family and, in the case of illness, other patients. Online, people use discussion boards and social networking websites to compare symptoms and treatment options as well as share acquired expert information. Directly and indirectly, people create cognitive authority as they go about their usual information-seeking habits.

Current service models for information professionals may or may not take into account this view of authority creation. Historically, patients and caregivers seeking health information typically expected to acquire traditionally authoritative information when they approached the library for assistance. That may still be the case, but the information landscape has long since repositioned itself. Before the Internet began facilitating two-way communication for anyone with online access and before anyone could self-publish anything online, the experts were the only ones who had publishing power. As a profession, it seems we have translated that expert notion of print-based authority into the online environment, despite the networked world's ability to bring patients together in order to share and judge information as a community. The website CureTogether (www.curetogether.com/), which allows patients to compare symptoms with one another, choose treatments

and track their conditions, is an excellent example of this newly found power at play.

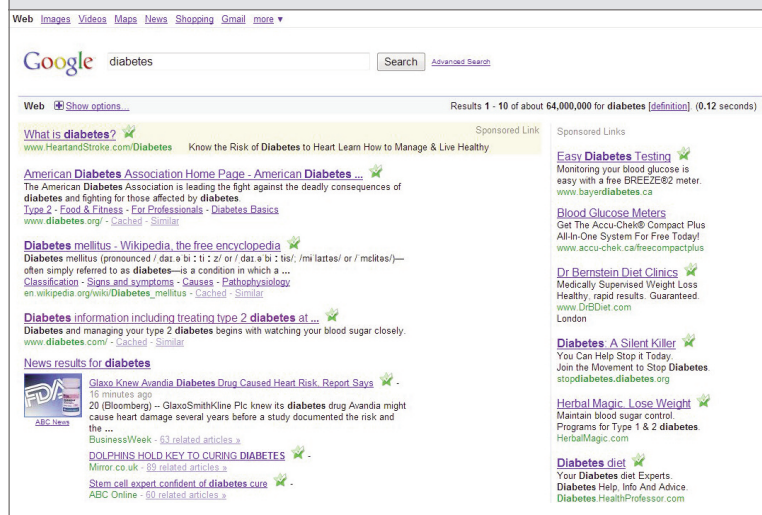
According to the American Library Association's Association for College and Research Libraries, the information literate student "examines and compares information from various sources in order to evaluate reliability, validity, accuracy, authority, timeliness and point of view or bias" (www.ala.org/ala/mgrps/divs/acrl/standards/informationliteracycompetency.cfm). As information professionals, we know that the standard guidelines for determining credibility include evaluating the author's professional credentials, the associated organization's aims and so on, and it has been considered our responsibility to also direct people to the relevant resources that meet those criteria. However, many cases that fall outside the lines of our traditional authority notions exist. For example, the gynecologist mentioned above meets the professional requirements for credibility surrounding a gynecological disease, but he provided incorrect information. A lawyer's website containing information about a pending class action lawsuit relating to life-threatening side effects of a prescription drug is obviously biased for the sake of recruiting clients, but it also might provide something to consider for someone having unexplained health issues. A patient wanting to explore complementary or alternative treatment options might not find them in physician-authored sources. Lay-led discussion boards providing social support for a chronic disease do not meet the traditional standards for authority, but they might be very useful for someone who is learning to cope emotionally with a new diagnosis.

Adding to the difficulty, of course, is the prevalence of health information online and deciding which information is truly useless. Thanks to our training, we know that not all information is reliable, but at the same time, we fundamentally have no way of knowing whether an Internet resource is useful. A multitude of examples can be found online of so-called "miracle" treatments for various diseases, which people may or may not dismiss as quickly as we might hope or imagine. However, simply because a non-mainstream treatment is advertised online does not automatically discount its ability to help someone. Patients of many diseases believe they find relief in natural treatments such as nutritional supplements and chiropractic care,

although medical doctors tend to downplay their potential effectiveness. Conversely, treatments prescribed by medical doctors that have been approved by a government regulatory agency are not necessarily safe or effective. Consider the “Fen-phen” situation from the 1990s, when doctors prescribed the fenfluramine and phentermine drug combination for obesity, and thousands of people filed lawsuits against the drug manufacturer due to either serious side effects or death. Websites abound with patients’ petitions stating that a particular drug has caused them to experience irreparable side effects. Clinical studies demonstrate the lack of antidepressant efficacy for many depressed patients and the decrease in antidepressant efficacy over time for others.

People frequently search for health information using Google. The Pew Internet & American Life Project’s website recently published a statement provided by a Google Health representative, stating, “Google is 100% committed to ranking websites objectively to provide the most relevant information to users. Websites cannot pay for higher search rank” (www.pewinternet.org/Commentary/2010/January/Health-Sites-Some-Are-More-Equal-Than-Others.aspx). *Objective* is a difficult term to define in this environment, and a few quick searches yielded some results that seem puzzling in light of their statement. In February 2010, the top Google search result for “depression” was depression.com, a website from the antidepressant manufacturer GlaxoSmithKline. The second result was the Wikipedia entry for *depression*, a source whose reliability is still under debate. A “diabetes” search yields similar results, with GlaxoSmithKline’s diabetes.com website as the third non-sponsored search result. The same company was in the news at the time of my searches, with reporters stating that Glaxo knew about research proving that their diabetes drug could cause

FIGURE 1. Google search result for “diabetes” with a pharmaceutical company as the fourth-ranked hit.



heart damage. This Google news result appeared right below the diabetes.com hit, as demonstrated in Figure 1. Imagine the confusion this result might cause.

At the same time, research tells us that while consumers do look for health information online quite often, they are also concerned about its quality. However, research is conflicting in regard to whether consumers look for certain cues or alternative sources to make decisions about information quality. Professional-looking design appears to be a very important factor in credibility judgments, as is user satisfaction: If consumers believe the site has met their information needs, they

consider it credible. A host of other factors can be found in the research. It would be very helpful if we could provide users with a list of online credibility factors or a rating system for authority. However, while several systems have been created, tested and published, with more in development, none seem to be in agreement, and research results vary greatly.

Despite these inconsistencies, the importance of non-traditional online consumer health information for many patients cannot be denied. Researchers presented work investigating the user-centered aims of online consumer health information at the 2009 ASIS&T Annual Meeting, demonstrating the social importance of newer modalities. For example, Rubenstein’s preliminary work on breast cancer discussion forums found that postings tend to provide very detailed accounts of users’ personal illness experiences, including related emotional states. Karimi and Poo’s study of medical bloggers’ reasons for blogging found that “enjoyment in helping others” was the most important factor, as reported in their contributed paper. According to a study described in Amos, Black and Gruzdz’s panel session presentation, personal diabetes bloggers link to other personal blogs, and blogs serve as outlets for links to reliable professional websites

and journal articles. These studies and other consumer health information behavior studies demonstrate people's perceived usefulness of freely available online resources, but perhaps in different ways from the presumably expert, non-biased and factual modalities we might be accustomed to recommending. Familiar standbys such as PubMed and the medical section of the library's print collections can no longer be expected to meet all consumer health information needs.

Implications for Professionals

What does this all mean for the future of our profession? Are we becoming extinct, with no way to determine how to direct people toward authoritative resources? Certainly not, although it does imply a slight change in *how* we provide the services we have always provided, which is at the heart of the Library 2.0 service philosophy. In 2006, Jack Maness offered four defining characteristics of Library 2.0 service: it is user-centered, it provides a multimedia experience, it is socially rich, and it is communally innovative. How could this philosophy operationalize itself in the context of consumer health information?

User-centered participation means that patrons create content within the context of the library's web resources. If your OPAC does not allow people to tag and write reviews of items in your collection, speak with your vendor about the possibility of adding that feature. If it is available in your system, advertise it. Together, your library's users can create their own sense of authority about your health-related collection, and reviewing these records periodically can inform your collection development decisions. Having a Facebook presence or a wiki allows for conversation to take place not only between you and your patrons, but among patrons as well. Encourage them to share links to Internet resources they have found useful. The University of Maryland Medical Center, which provides a substantial amount of online health information, has a presence on Facebook, Twitter and YouTube; consider linking to them through your library's social networking profiles. Libraries are community organizations, and it is perhaps our responsibility to facilitate that sense of community, whether in the library building or online.

Information science research is demonstrating that many of today's

online users, especially younger people, are not quite as interested in reading text-based resources with technical language as people of older generations. Having grown up with computers, video games and other forms of digital entertainment (sometimes all playing at once), they enjoy receiving information presented in interactive, multimedia formats. As a result, many newer formats for conveying information are growing in popularity. Cell phone applications that help people meet their health needs are growing in exponential numbers every day. A quick browse of my own phone's "Health" applications revealed a free downloadable application called HelpDiabetes, which assists diabetics in making food choices by calculating calories, carbohydrates, fats and proteins in a given meal. An emerging video game genre known as "serious games" tends to have prominent educational goals and has also shown promise in providing social support to patients suffering from various conditions. Watch for developments in these areas, and as you find them, consider developing pathfinders that include new online communication modalities. Generally speaking, the top hits of Google searches for health conditions return items in four categories: (1) Wikipedia articles, (2) resources from government-based entities such as the National Institutes of Health, (3) non-profit advocacy organizations such as the Alzheimer's Association and (4) information that might be considered unreliable, especially in the Sponsored Links area of the page. These resources overwhelmingly present information in a traditional text-based format. Newer resource formats are frequently buried in the search results, and users tend to only look at the first few results.

Above all, in this era, it is important to maintain a sense of balance when recommending health-related resources. As you introduce non-traditional health information resources into your reference practice, explain the positives and negatives of the various options. For example, if a patron's loved one has just been diagnosed with Alzheimer's disease and wants more information about it, you might provide the URL of the Alzheimer's Association as well as early-stage caregiver information, but find out whether the patron is interested in related research articles before recommending PubMed. Make sure people are aware that "experts" and "expert sources" do make mistakes, and that sometimes valuable information, support and engaging interaction can

be found in unexpected places. I am a member of various online health discussion boards for both research and personal purposes, and the number of times I see a new member post something such as “I wish I had known this forum was here, because I’ve been struggling with this disease alone for a long time” is very telling.

In conclusion and summary, we cannot necessarily make authority judgments for people in the domain of online consumer health information, even if we as information professionals consider it to be authoritative based on our own criteria. The boundaries are too blurry, and what meets one

person’s needs for mainstream empirical research based on randomized controlled trials will not match another’s desire for learning about complementary treatment options or peer-based discussion boards. However, we can certainly help people find what is available in a broad range of related areas and guide them toward creating their own conclusions. In light of this, a broad program of research is needed in this area, with practitioners and researchers in both public service and web development settings working together to determine how we can address a rapidly growing spectrum of health information expectations. I invite you to join the exploration. ■

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