

# PLAIN LANGUAGE IN HEALTHCARE

## What Lawyers Need to Know About Health Literacy



BY CHRISTOPHER R. TRUDEAU

Poor health communication is one area that is often overlooked. But it affects everyone, from patients and providers to health systems, drug companies, insurers, government agencies, and the lawyers who represent them. Think about it—how providers and healthcare organizations communicate with patients is critical for patients to be able to comply with treatment regimens, make informed decisions, and, ultimately, be active participants in their own health. Consider the following well-known example:

An 89-year-old man with dementia is diagnosed with an ear infection and is prescribed an oral liquid antibiotic. His wife understands that he must take one teaspoon twice a day. After carefully studying the bottle's label and not finding administration instructions, she fills a teaspoon and pours it into his painful ear.<sup>1</sup>

This example is not an anomaly. Most patients have low health literacy. Health literacy is “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”<sup>2</sup> In other words, if a person cannot figure out where to go to be treated for a certain condition, he or she either doesn't seek treatment for the condition or uses a more costly method that burdens the entire system.<sup>3</sup> So an individual's ability to understand a treatment plan and navigate the healthcare system depends on his or her health literacy. This seems straightforward, but it's not as simple as it sounds. “Health literacy requires knowledge

from many topic areas, including [knowledge of the] body, healthy behaviors, and the workings of the health system.”<sup>4</sup>

### How prevalent is low health literacy?

Most people in the U.S.—approximately 88 percent—have at least some problems understanding health information. That’s not a misprint—88 percent of people have some problems understanding health information. Research divides patients into four categories of health literacy: below basic, basic, intermediate, and proficient.

“Below basic indicates no more than the most simple and concrete literacy skills.”<sup>5</sup> Fourteen percent of adults surveyed had below basic health literacy. The basic level “indicates skills necessary to perform simple and everyday literacy activities.”<sup>6</sup> Twenty-two percent of adults surveyed had a basic health-literacy level. This means that 36 percent of adults—more than 1 in 3—had below basic or basic health-literacy levels and, at best, understand simple documents that contain visual aids and uncomplicated language.<sup>7</sup>

The majority of adults—53 percent—had an intermediate health-literacy level. The intermediate level “indicates skills necessary to perform moderately challenging literacy activities.”<sup>8</sup> The health-literacy level with the most proficient comprehension was also the lowest percentage—12 percent. This level “indicates skills necessary to perform complex and challenging literacy activities.”<sup>9</sup> Adults with a proficient health-literacy level are more likely to be able to gather relevant information on their own, process that information, and make informed health decisions.<sup>10</sup>

### What factors contribute to low health literacy?

Health literacy affects many, but groups such as the elderly, minorities, and people with lower education and income are more likely to have limited health literacy.<sup>11</sup> Of course, it is no surprise that education plays an important role in a

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person’s health literacy. After all, basic literacy—the ability to use written material to function in society—is the starting point for health literacy.

But someone who has a high literacy level could have a low health-literacy level. Many lawyers read at above the 16th grade level; they graduated college and spent three years in law school, after all. But many non-healthcare attorneys, and probably some healthcare attorneys, are not all that familiar with medical terminology. For example, many do not know that medical shorthand for both eyes is “OU.” So if an ophthalmology practice gives a person a patient summary that says “instill one drop, OU, 2x daily,” a vast majority of people would have trouble understanding what to do. (This actually happened to me, by the way.) Also, if a doctor explains to a patient that he or she “presented with nephritis,” a patient with limited health literacy might not intuitively understand that diagnosis. Wouldn’t it be far easier to call this a kidney infection? In short, being health literate goes far beyond the ability to read or write at a certain level; it incorporates many additional skills such as the ability to understand medical terminology, the ability to understand and use the healthcare system, and the ability to understand numbers and risk statistics.

Another factor contributing to health literacy is a person’s socioeconomic status. Low socioeconomic status can affect health literacy in a number of ways. First, these patients might not have access to the same educational opportunities as other patients, resulting in low literacy levels for most in that patient population. Additionally, patients with low socioeconomic status tend not to have access to

#### **FAST FACTS**

**Health literacy is a person’s ability to understand and use information to make appropriate health decisions.**

**Approximately 88 percent of people in the U.S. have some problems understanding health information.**

**Because the vast majority of patients have low health literacy, every piece of patient information must be written in plain language; aim for material written at the sixth-grade level.**



important information (e.g., they may not have Internet access), making it challenging for them to gather relevant facts concerning their health. They also might not have the financial means to receive regular medical treatment, which makes it more difficult to develop meaningful, trusting relationships with providers.<sup>12</sup>

Another contributing factor to a patient's health literacy is culture. For example, it is well documented that African Americans have a history of not receiving equal medical treatment, making them more likely not to trust providers. This mistrust can lead to increased refusal for treatment.<sup>13</sup> And, of course, culture also includes language barriers. Not everyone in the U.S. is a native English speaker, as we all know. These language barriers, not surprisingly, create additional problems for effective health communication.

### What is being done to address low health literacy?

Low health literacy is a problem the world is starting to address. "Evolving research suggests that low health literacy among patients, and the public generally, is a significant problem that can undermine health care access and quality in ways that increase costs to patients, providers, and taxpayers."<sup>14</sup> Because of this, the United Nations has agreed on a goal of improving health literacy. The UN stresses "that health literacy is an important factor in ensuring significant health outcomes and... call[s] for the development of appropriate action plans to promote health literacy."<sup>15</sup>

In 2010, the U.S. published its *National Action Plan to Improve Health Literacy*, which, among other things, envisions a healthcare system that provides people with "access to accurate and actionable health information," "[d]elivers person-centered health information and services," and "[s]upports

lifelong learning and skills to promote good health."<sup>16</sup> Unfortunately, even though the Affordable Care Act introduced sweeping change to the U.S. healthcare system, very few of its more than 2,000 pages of regulations directly or indirectly address improving health literacy or patient understanding of health information.<sup>17</sup> So while many governmental organizations do help to combat low health literacy, the actual creation of health-literate materials and programs that further promote health literacy are ultimately left to healthcare organizations. This is where we—the lawyers—come in.

### Why should attorneys care about health literacy?

We now know how important combating low health literacy is to public health. But it is also particularly important to private healthcare organizations, health insurers, drug companies, and medical device manufacturers. Low health literacy has been empirically linked to increased hospital readmission rates, lack of informed consent, lower medication adherence rates, and, ultimately, higher healthcare costs.<sup>18</sup> Given these links, it is easy to see why health literacy can affect lawyers.

If you represent plaintiffs in medical malpractice cases, understanding health literacy directly affects your practice. Not only will you better understand your clients, but it will be much easier for you to appreciate what your clients understood—or likely failed to understand—during their treatment. You can then, for example, better assess if the healthcare organization, provider, or drug company used unnecessarily complicated documents or had complex organizational procedures that affected your client's ability to understand and make an informed decision. You can use this lack of understanding to create viable arguments, which may add fuel to your medical malpractice case. This is the sword of health literacy, as I call it.

If you represent healthcare organizations, drug companies, or medical device manufacturers (or if you are in-house counsel for one), you likely had a chill when you read the last paragraph. The thought of having documents and procedures used against your client is not a pleasant one. But the good news is that you can do something about it and directly add value to the services you provide. Nearly every healthcare organization would do well to revisit and redesign its communication practices to ensure patient understanding. This will involve more than just revising documents—it will take a concerted effort to rethink how the organization interacts with its patients. As competition increases, healthcare organizations are starting to differentiate themselves by focusing on patient-centered care. So by helping your clients address the way they communicate with patients, you will help them achieve their organizational goals while better protecting them from malpractice litigation. This is the shield of health literacy.

Health literacy can affect other areas of practice, too—like Social Security, Medicare and Medicaid, consumer protection, and estate planning. For example, consider estate-planning clients seeking a medical directive. Based on statistics, we know that many of these clients likely have limited health literacy, so when they ask for a medical directive, estate-planning attorneys should walk them through each step of the process. These clients may not understand what palliative care means or the medical options presented to them. To help combat this problem, California and Pennsylvania have developed easy-to-read advance directives (written at the third-grade level), which are available at <https://www.ih4health.org/our-services/advance-directive>. Of course, there are any examples of individuals (most of whom are not health lawyers) using their knowledge of health literacy to improve the lives of others. We lawyers should start doing the same.

### How can you develop health-literate materials?

Creating health-literate materials involves a host of factors that could fill up this edition of the *Bar Journal*. Here are a few tips to help get you started.

#### Use plain language

Because the vast majority of patients have low health literacy, every piece of patient information must be clear and understandable. The goal should be to write material that is easily understood by patients with a sixth-grade education. This is not easy, but it can be done. One tip is to remove any medical or legal terms that are not essential to the patient's understanding. Even though it is tempting to use medical or legal terms to "be precise," this precision is lost on the vast majority of patients. And if you must use a medical or legal term, do everyone a favor and explain, clearly, what that term means.<sup>19</sup> Remember, if patients are confused before treatment and something unexpected happens later, they become frustrated, which might make them seek out an attorney to discuss the matter.

#### Be careful when communicating risk information

Patients have even more trouble with numbers than they do with words alone. This is generally referred to as a patient's numeracy. For example, many patients have trouble figuring out if a .09 percent chance of something happening is worse for them than a risk of .009 percent. To combat this numeracy problem, use natural frequencies instead of conditional probabilities. That means, say 2 of 1,000 people instead of .2 percent of people. Also, use absolute risks instead of relative risks. For example, if a patient's risk will double if he or she takes a certain medication, frame the risk in absolute terms: "Your risk will increase from 1 in 7,000 to 2 in 7,000."

Finally, when presenting risk in documents, use meaningful graphics such as icon arrays to better help convey this information to patients.<sup>20</sup>

### Conclusion

Low health literacy is a problem that affects many. How providers, insurers, drug companies, and healthcare organizations communicate with patients is critical for patients to be able to comply with treatment regimens and make informed decisions. We lawyers play an important role in this. Through our role as counsel, we can do much to help create clear, health-literate materials and develop processes that not only better protect organizations, but also explain health information to patients in ways they can more easily understand. Simply put, we can create win-wins. Let's make that our goal. ■



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### ENDNOTES

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3. Eichler, *The Costs of Limited Health Literacy: A Systematic Review*, 54 Intl J Public Health 313–324 (2009).
4. See *National Action Plan*, p 5.
5. National Center for Education Statistics, *The Health Literacy of America's Adults* (2006), p 5.
6. *Id.*
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11. See *National Action Plan*, p 8.
12. Clark, *Using Law to Fight a Silent Epidemic: The Role of Health Literacy in Health Care Access, Quality & Cost*, 20 Annals of Health L 253, 263 (2011).
13. Nelson, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, 94 J Nat'l Med Ass'n 666, 667 (2002).
14. See *Using Law to Fight a Silent Epidemic*, p 255.
15. United Nations Economic and Social Council, *Ministerial Declaration of the 2009 High-Level Segment: Implementing the internationally agreed goals and commitments in regards to global public health* (2009).
16. See *National Action Plan*, p 8.
17. Sommers & Mahadevan, *Health Literacy Implications of the Affordable Care Act* (2010) (discussing the direct and indirect mentions of health literacy in the Affordable Care Act).
18. See *Unequal Treatment*, 94 J Nat'l Med Ass'n 666.
19. Trudeau, *The Public Speaks: An Empirical Study of Legal Communication*, 14 Scribes J Legal Writing 121 (2012).
20. See, e.g., Gett, *Evaluating Informed Consent for Colonoscopy*, 4 Surg Laparosc Endosc Percutan Tech 345–352 (2014).