

## POLICY FORUM

### The Role of Universal Health Literacy Precautions in Minimizing “Medspeak” and Promoting Shared Decision Making

Lara Killian, MA, MLIS, and Margo Coletti, AMLS

#### Abstract

Shared decision making (SDM), a collaborative process whereby patients and professionals make health care decisions together, is a cornerstone of ethical patient care. The patient-clinician communication necessary to achieve SDM depends on many factors, not the least of which is a shared language (sometimes with the aid of a medical interpreter). However, even when a patient and clinician are speaking the same mother tongue, the use of medical jargon can pose a large and unnecessary barrier. This article discusses how health care professionals can use “universal health literacy precautions” as a legal, practical, and ethical means to enhance SDM and improve health care outcomes.

#### Case of Language Barrier’s Impact on Patient Autonomy

Patient X, a 56-year-old construction worker, visits the emergency department (ED) with pain and swelling in his right calf. He can walk on his leg with a limp and considers the pain to be bearable. He would prefer to just “power through” whatever is causing the discomfort. This is his first ED visit. He is here to placate his wife, who was alarmed at the progression of the swelling over the last 24 hours.

A physical exam reveals a slightly elevated temperature of 99 degrees and blood pressure of 150/110. Blood cultures, a creatine phosphokinase (CPK) test, and a C-reactive protein (CRP) test are ordered. When asked about any previous trauma to his leg, Patient X is confused. Has he had “trauma”? He considers himself a calm person, not easily alarmed or “traumatized.” He asks the physician (Dr. Y) why they need his blood and is told that the cultures may reveal the agent or pathogen responsible for his condition. Patient X is becoming alarmed. To him, an “agent” sounds like a person. A “pathogen” sounds like a “psychopath” but it can’t mean that, except the doctor said something about the “culture.”

Dr. Y is running behind; it will be at least two hours before she can return with the bloodwork results to confirm her diagnosis, prescribe appropriately, and either discharge or admit Patient X. This leaves Patient X with two hours to worry and try to explain the situation to his wife over the phone.

When Dr. Y returns, Patient X is fearful and distressed, and his head is full of confusing words: culture, pathogen, agent, and trauma. Next is a new word: cellulitis. Dr. Y tells him cellulitis is an “inflammation of the skin and subcutaneous tissues.” Patient X looks at his leg with alarm. What does “subcutaneous” mean? And “inflammation”—does that mean his leg is on fire? It certainly feels like it is. The physician recommends treatment: the cellulitis is severe enough to warrant observation for 24 hours. Dr. Y tells Patient X that he can either go home with a prescription for oral antibiotics and bed rest, or he can stay for IV antibiotics and observation. She asks him if he has any questions about this choice. His head is swimming with half-formed questions but all he can come up with is, “What do *you* think I should do?”

Coming from a place of confusion and fear, Patient X has ceded his autonomy and all decision making to the physician. Fear and confusion can be especially prevalent in EDs and ICUs, and communication barriers exist in all health care settings. This article examines not only how language barriers occur and interfere with shared decision making, but also how health care staff can remedy this problem by using new communication tools.

### **Medical Terminology and Patient Lingo as Barriers to Shared Decision Making**

Every profession has its own vernacular. Contractors, computer engineers, attorneys, physicians—we all have a different jargon. The customer, client, or patient often struggles to understand important information conveyed in unfamiliar and technical terms, frequently at a fast pace. Medical terminology is collectively referred to by the Medical Library Association as “medspeak” [1]. Patients’ abilities to sift critical facts from insignificant details within this jargon jungle can have serious consequences for their decisions and actions regarding their health conditions.

Shared decision making (SDM), a collaborative process whereby patients and professionals make health care decisions together [2], is a cornerstone of ethical patient care. The patient-clinician communication necessary to achieve SDM depends on many factors, not the least of which is a shared language (sometimes with the aid of a medical interpreter). However, even when a patient and professional are speaking the same mother tongue, the use of medspeak can be an unnecessary barrier to SDM.

A patient who learns she has had a myocardial infarction (medspeak term) might hear the diagnosis, including lab results (more medspeak), as unintelligible. In fact, the patient might grasp the seriousness of the situation only from the expression on the physician’s face. When asked if she has any questions, the answer might be “no,” because the patient does not want to appear ignorant or is overwhelmed with questions and doesn’t know where to start. Patient X was only able to ask one question: “What do *you* think I should do?”

Another factor in patient-clinician communication is that patients often have their own lingo. A “deep study” (depression), “athletic fits” (epileptic seizures) [1], or a discharge from a patient’s “oven door” (vagina), are colloquial or even individual terms, each indicating a condition that needs to be addressed. The clinician sometimes has to act as a two-way interpreter, clinician-to-patient and patient-to-clinician. Patients’ anxiety and symptoms can add to the [communication barrier](#). When anxious, in pain, or compromised by illness, even patients and family members with high health literacy can mishear, misinterpret, or forget vital information—just at the time when it’s most critical to understand it.

### **Health Literacy and Health Literacy Universal Precautions**

Only 12 percent of adults in the US [3] are considered to have high health literacy proficiency. An even smaller number of American adults, 9 percent, have adequate numeracy skills [3] to ensure that correct medication dosages are taken, for example [4]. In Canada, by contrast, 46 percent of adults between 16 and 65 years of age are considered to have adequate health literacy, but that number falls to 12 percent for those older than 65 [5].

Health literacy at its core is being able to find, understand, and use information about health. Often, health care professionals assume that patients and families understand what they’ve been told [6]. However, it’s not enough to think that a nod or silence—or even a “yes”—means comprehension. A blank look—common when a person is overwhelmed—is a good indication that there has been a communication breakdown [7]. Tools are needed to translate confusing medical vocabulary, confirm understanding, fill in gaps, and ensure that patients are encouraged to ask questions and actively learn about their health conditions.

Health Literacy Universal Precautions, a toolkit created by the Agency for Healthcare Research and Quality (AHRQ), is a series of steps that health care professionals can take to ensure that patients understand information relevant to their health and can participate in their own health care. The toolkit, freely available online, includes 21 tools to help improve communication with and care for patients and families at all health literacy levels [8]. Designed for busy health care environments, the toolkit includes techniques such as encouraging questions in a non-shaming atmosphere, using educational materials effectively, and the “teach-back” method for assessing patient comprehension. The teach-back method is simple: after explaining a patient’s condition, options, or next steps—such as what medication will be taken, how much, and when—the clinician asks patients to state in their own words what they will do next or what they understood from the clinician’s statements. If patients have understood what the clinician has told them, they’ll be able to explain it back. If they haven’t, the clinician will know immediately that he or she needs to go over the important details again and try

again to confirm understanding. Much like routine hand washing, AHRQ recommends that clinicians use these tools on the assumption that every patient may have limited health literacy [8].

### **Why Should Health Care Professionals Use Health Literacy Universal Precautions?**

According to the *AMA Code of Medical Ethics*, “Physicians have a responsibility to adopt, or advocate for, policies and procedures to ensure that ... the patient/surrogate receives information needed to make well-considered decisions about medical treatment and give informed consent to future treatment” [9]. There are ethical, legal, and practical rationales for the use of universal health literacy precautions. We make our case, with the help of Patient X and Dr. Y, below.

*Dignity.* Respect for patient autonomy, a key principle of medical ethics, begins with respect for the intrinsic moral worth of the patient and his or her dignity. Thomas Nairn [10], senior director of ethics, Catholic Health Association, states that “Health literacy is also—and perhaps even primarily—an ethical issue involving the dignity of the patient and the very integrity of health care” [11]. He further notes that “the relationship between the patient and the health care professional necessarily entails a difference in power. The power of the health care professional can be used to enhance the dignity of the patient or contribute to his or her denigration” [12]. The use of technical jargon in any profession can be a means of wielding power over the listener. Sociologist Karen Sternheimer argues that “Social groups create special language—like jargon—in part to make communication short cuts, but mostly to clearly delineate who is a member and who is not” [13]. Using med speak can undermine the patient’s dignity by creating boundaries between the patient and the clinician. Avoiding med speak altogether, or explaining terminology when its use is unavoidable, respects patient dignity and is the ethical choice. When Patient X asks why his blood is being taken and Dr. Y tells him that the cultures may reveal the agent or pathogen responsible for his condition, she has not answered his question in any meaningful way, given his low level of health literacy. He may feel ignorant or “less than” because he does not understand her answer.

*Autonomy.* Exercising the right of self-determination is contingent on a patient’s understanding of relevant information. The clinician’s ensuring that the patient understands appropriate diagnostic and treatment information is an essential component of [informed consent](#), a process that is ongoing throughout the clinical encounter—whether or not a consent form is involved. Informed consent happens informally when the patient is directed to strip for an exam. (“Please take off your clothes from the waist down and put this robe over your bottom half, so the doctor can look at your leg.”) It is the patient’s understanding of the information presented and willingness to participate in his or her own care that enables SDM and informed consent to take place. A patient who doesn’t understand the possible next steps in his or her care or the risks of a particular treatment cannot give informed consent. Patient X did not

have enough understanding of his condition to participate in SDM and make an informed decision about his treatment. Dr. Y's explanations were a jumble of jargon to Patient X, not a foundation on which to base an informed consent.

*Risk management.* Breakdowns in patient-physician communication can lead to legal liability [14]. In this case, Dr. Y could have used the teach-back method to ask Patient X to explain to her what he understood his condition and options to be. If his preference was to go home with the prescription for oral antibiotics and the expectation of bed rest, Dr. Y could have asked him to explain his next steps, which should involve filling the prescription. Dr. Y would be managing the risk of a complaint being filed with the hospital (because Patient X wasn't adequately cared for), because she would have confirmed understanding with her patient. Studies have shown that improved communication between health care practitioners and patients leads to improved patient outcomes, fewer medical errors, and lower rates of malpractice claims [15]. In fact, primary care physicians with no [malpractice claims](#) differ significantly in their communication skills from those who have experienced malpractice claims [16].

*Regulatory compliance.* In the US, there are several accrediting bodies for health care organizations. Accreditation from at least one of these organizations may be essential for providers to obtain insurance reimbursement, fulfill state regulatory requirements, and acquire and maintain a competitive advantage, among other benefits [17]. Three of these organizations address health literacy concerns within their regulations: the Joint Commission, the National Committee for Quality Assurance, and the Utilization Review Accreditation Commission [18]. The AHRQ Toolkit maps tools to specific regulations of these three accrediting bodies and provides a "crosswalk" (i.e., tables) to navigate these regulations [18].

*Patient safety and practical implications.* Communication is a patient safety issue as well. Making sure patients understand their condition or treatment and that they know what the next steps are and what to watch out for means they're less likely to return to the health care professional's office or, worse, the ED [19]. In a research study context, patients with a firm grasp of the research steps, visits, and procedures are more likely to stay enrolled for the duration of the study [20]. Enabling people to take an active role in their own care through ensuring their comprehension of relevant information makes the health system more efficient for everyone and leads to better health outcomes overall [15].

### **How Could Patient X's Clinical Experience Have Been Better?**

The clinical encounter between Patient X and Dr. Y could have been improved with the use of Health Literacy Universal Precautions tools. Instead of asking the patient whether he had experienced trauma to his leg, Dr. Y could have used Tool #4, "using plain language," and asked if he'd had any cuts or scratches on it [8]. Before ordering the blood

draw, she could have told the patient his blood would be examined for germs that might be causing an infection in his leg. Before leaving the exam area, she might have asked him, "If your wife calls, what will you tell her about your leg? Can you explain to her why we are taking a sample of your blood?" This is an example of the teach-back method—Tool #5 in the AHRQ Toolkit [8]—whereby patients need to explain in their own words what they have understood about their condition. Dr. Y. will also need to outline the treatment choices and engage her patient in the decision-making process. Why might Patient X be better (or worse) off at home? Does he have to climb stairs several times a day to use the bathroom? Does he have help at home? Will he be able to remain autonomous and to take care of himself as he used to? Are there any concerns about Patient X retaining dignity if he needs to be bathed or toileted by his wife?

### Conclusion

Health care professionals can and should use Health Literacy Universal Precautions as an ethical, legal, and practical means to enhance SDM and improve health care outcomes. Not using health literacy precautions could add avoidable costs to a burdened health care system. In its Toolkit, the AHRQ provides a path. Can we find a way to follow it?

### References

1. Medical Library Association. What did my doctor say? <http://www.mlanet.org/p/cm/ld/fid=580>. Accessed October 4, 2016.
2. Elwyn G, Frosch D, Thomson R, et al. Shared decision making: a model for clinical practice. *J Gen Intern Med*. 2012;27(10):1361-1367.
3. Centers for Disease Control and Prevention. Health literacy for public health professionals: health literacy in the United States. <http://www.cdc.gov/healthliteracy/training/page669.html>. Accessed October 19, 2016.
4. Griffey RT, McNaughton CD, McCarthy DM, et al. Shared decision making in the emergency department among patients with limited health literacy: beyond slower and louder [published online ahead of print September 19, 2016]. *Acad Emerg Med*. doi: 10.1111/acem.13104.
5. Canadian Council on Learning. *State of Learning in Canada: No Time for Complacency*. Ottawa, Ontario: Canadian Council on Learning; 2007. [http://www.literacy.ca/content/uploads/2012/02/NewSOLR\\_Report.pdf](http://www.literacy.ca/content/uploads/2012/02/NewSOLR_Report.pdf). Accessed October 19, 2016.
6. Calkins DR, Davis RB, Reiley P, et al. Patient-physician communication at hospital discharge and patients' understanding of the postdischarge treatment plan. *Arch Intern Med*. 1997;157(9):1026-1030.
7. Osborne H. Jargon, acronyms, and other confusing terms. Health Literacy Consulting. <http://healthliteracy.com/2016/02/01/health-care-homonyms-jargon-and-other-confusing-words-2/>. Published February 1, 2016. Accessed October 19, 2016.

8. Brega AG, Barnard J, Mabachi NM, et al. *AHRQ Health Literacy Universal Precautions Toolkit*. 2nd ed. Rockville, MD: Agency for Healthcare Research and Quality; 2015. AHRQ Publication 15-0023-EF.  
[https://www.ahrq.gov/sites/default/files/publications/files/healthlittoolkit2\\_4.pdf](https://www.ahrq.gov/sites/default/files/publications/files/healthlittoolkit2_4.pdf). Accessed September 27, 2016.
9. American Medical Association. Opinion 2.1.5 Reporting clinical test results. *Code of Medical Ethics*. <https://www.ama-assn.org/sites/default/files/media-browser/code-of-medical-ethics-chapter-2.pdf>. Published 2016:5. Accessed January 27, 2017.
10. Nairn T. What we have here is a failure to communicate. The ethical dimension of health literacy. *Health Prog*. 2014;95(4):61-63.
11. Nairn, 61.
12. Nairn, 63.
13. Sternheimer K. The sociology of jargon. *Everyday Sociology Blog*. December 2, 2010. <http://www.everydaysociologyblog.com/2010/12/the-sociology-of-jargon.html>. Accessed October 18, 2016.
14. Huntington B, Kuhn N. Communication gaffes: a root cause of malpractice claims. *Proc (Bayl Univ Med Cent)*. 2003;16(2):157-161.
15. Cordasco KM. Obtaining informed consent from patients: brief update review. In: Agency for Healthcare Research and Quality. *Making Health Care Safer II: An Updated Critical Analysis of the Evidence for Patient Safety Practices*. Rockville, MD: Agency for Healthcare Research and Quality; 2013. Evidence Reports/Technology Assessments 211.  
<https://www.ncbi.nlm.nih.gov/books/NBK133402/>. Accessed January 27, 2016.
16. Levinson W, Roter DL, Mullooly JP, Dull VT, Frankel RM. Physician-patient communication: the relationship with malpractice claims among primary care physicians and surgeons. *JAMA*. 1997;277(7):553-559.
17. BHM Healthcare Solutions. The big five healthcare accreditation organizations—side by side comparison. <http://bhmpc.com/pdfs/Accreditation-Comparison-Tool.pdf>. Accessed December 1, 2016.
18. Agency for Healthcare Research and Quality. Using health literacy tools to meet PCMH standards.  
<http://www.ahrq.gov/sites/default/files/wysiwyg/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/pcmh-crosswalk.pdf>. Published January 2015. Accessed October 20, 2016.
19. Baker DW, Gazmararian JA, Williams MV, et al. Functional health literacy and the risk of hospital admission among Medicare managed care enrollees. *Am J Public Health*. 2002;92(8):1278-1283.
20. Leak C, Goggins K, Schildcrout JS, et al; Vanderbilt Inpatient Cohort Study. Effect of health literacy on research follow-up. *J Health Commun*. 2015; 20(suppl 2):83-91.

**Lara Killian, MA, MLIS**, is the librarian educator in charge of patient education for the Nova Scotia Health Authority, in Halifax, Nova Scotia, Canada, where she manages the patient education pamphlet collection, conducts training on health literacy and consumer health, and offers a plain language review service to hospital staff. She is also an author on a Cochrane review on green tea and weight loss.

**Margo Coletti, AMLS**, is the director of knowledge services at Beth Israel Deaconess Medical Center in Boston. Her team provides knowledge-based and evidence-based information, resources, and systems and services. Her special interests include clinical medical and institutional ethics, evidence-based medicine, health literacy, open access journals and public policy, and knowledge management.

### **Acknowledgements**

The authors would like to thank Michelle Eberle (at the Massachusetts Library System, formerly of the National Network of Libraries of Medicine) and Jackie Zoppa (at the Nova Scotia Health Authority) for reviewing the manuscript prior to submission.

### **Related in the *AMA Journal of Ethics***

[Difficult Patient-Physician Relationships and the Risk of Medical Malpractice Litigation](#), March 2009

[Language Barriers and the Patient Encounter](#), August 2007

[Language Barriers in the Emergency Room](#), April 2012

[The Patient's Piece of the Informed Consent Pie](#), August 2008

[Language-Based Inequity in Health Care: Who Is the "Poor Historian"?](#), March 2017

[Strategies for Acing the Fundamentals and Mitigating Legal and Ethical Consequences of Poor Physician-Patient Communication](#), March 2017

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2017 American Medical Association. All rights reserved.  
ISSN 2376-6980**