



Women & Health Literacy

Toni Cordell lost her uterus because she couldn't read very well. When she was in her mid-30s, she suffered from what she called a "bulging" in her vaginal area. So she did what any woman would do: She went to see her doctor.

"That's an easy repair," her doctor said. And he scheduled her for surgery.

"Typical of most of my life, I didn't ask the right questions," says Ms. Cordell, now 62, of Newnan, GA.

The night before the surgery, she recalls sitting across from the admissions clerk at the hospital, who pushed paper after paper at her to sign. But Ms. Cordell, who read on about a fifth-grade level, knew it would take hours to read all those papers, and doubted she'd be able to understand them anyway. Plus, she says, "I knew they wouldn't let me have the surgery unless I signed." And she really needed the surgery. So she signed.

Six weeks after the surgery, during a follow-up checkup, Ms. Cordell learned the "easy repair" was actually a hysterectomy. "The concept of not realizing the magnitude of the surgery still frightens me," she says today.

Yet today—even 30 years later—hers is a situation millions of Americans find themselves in nearly every time they visit a health care professional, try to read medication information, or are presented with medical forms. Nearly half of all American adults—90 million people—have difficulty understanding and acting upon health information, notes the Institute of Medicine (IOM) in its report, "Health Literacy: A Prescription to End Confusion." The IOM, a non-profit, non-governmental entity that provides science-based advice on matters of biomedical science, medicine and health, defines health literacy as "The ability to obtain, process, and understand basic health information and services needed to make appropriate health decisions."¹

Health literacy is not to be confused with the ability to read, although at least a quarter of Americans read at the fifth grade level or below, while the majority of patient education materials are written at or above the 10th-grade level.² Nor does it mean that someone is learning disabled or slow. "My own father has two master's degrees in math and he can't keep the various medications he's taking straight," says Laurie Scudder, RN-C, PNP, a pediatric nurse practitioner in Columbia, MD, and board member of the Partnership for Clear Health Communication, a national coalition of more than 100 organizations working to promote awareness and solutions around the issue of low health literacy. In fact, less than half the adult population in the U.S. understands many commonly used medical words.³

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And that, says the IOM's 2004 report, costs the American health system some \$58 billion a year.¹

"Some studies find low health literacy is the single biggest contributor to poor health outcomes," says Ms. Scudder. For instance, she notes, about a third of the American public doesn't understand the written information they receive about their medication. "That doesn't mean these people aren't educated or aren't intelligent," she says. "It means that health care has created its own language that is increasingly difficult to follow."

Holding the Wrong Assumptions

Part of the problem, says Sunil Kripalani, MD, MSc, a health literacy researcher and assistant professor of medicine at Emory University's School of Medicine in Atlanta, GA, is the underlying assumption health care professionals have about their patients. "Most physicians assume that patients understand health care information and instructions," he says. "If anything, we should assume the opposite."

For instance, telling a patient to take a teaspoon of the medication is useless if you don't specify which teaspoon to use, says Ms. Scudder. That's why in her pediatric practice she now routinely gives her patients' parents a medicine spoon or syringe when she prescribes a liquid medication.

"There are so many times I'm in a rush and trying to educate a patient and they don't understand what I'm saying and I'm not realizing that even my simple instructions are misunderstood," says Ms. Scudder.

Overall, studies find, patients recall or comprehend as little as half of what physicians say during an office visit. Yet in one study, researchers found that physicians rarely assessed their patients' recall or comprehension of new concepts.⁴

Low Health Literacy Has Many Faces

Low health literacy affects people regardless of race, ethnicity, income level and geographic location. Of the 90 million estimated to have problems understanding health information, just 15 percent were born outside the country, and only five percent describe themselves as having a learning disability. Actually, the majority of adults with poor literacy are white, native-born Americans.⁵

Still, the IOM report finds, the problem is greatest among older people, those with limited education and those with limited proficiency in English, immigrants, for example.¹ The Center for Health Care Strategies finds that a disproportionate number of minorities and immigrants are estimated to have literacy problems, including 50 percent of Hispanics, 40 percent of African Americans, and 33 percent of Asians.² It is one major reason for the health disparity found between minorities and Caucasians, says Ms. Scudder.

Health literacy also seems to affect women more than men, possibly because women interact more with the health care system.⁶ Which, in turn, significantly affects women's health.

For instance, studies find that women who have low health literacy are significantly more likely to have never had a Pap smear in their life, or not to have had a mammogram in the past two years. They're also less likely to breastfeed.⁶

It affects women's overall quality of life, as well. One study of nearly 1,000 women with breast cancer found that nearly half said the information they received on several medical aspects of their condition was "incomprehensible or incomplete." The worse the communication with the medical staff, the study found, the worse the women's

quality life remained for up to four years after their diagnosis.⁷

Other studies find that people with low health literacy are hospitalized more, have more difficulties using metered dose inhalers (for asthma and other lung conditions), and have worse HbA1c levels, an indication of how well people with diabetes manage their blood sugar levels over time,⁶ than those with higher literacy levels.

In one study of 114 patients with diabetes conducted in two public hospitals, researchers found only half of those with inadequate health literacy knew the symptoms of hypoglycemia, or low blood sugar, compared to 94 percent of those with adequate literacy.⁸

Research also suggests that people with low literacy make more medication or treatment errors^{9,10} and are less likely to comply with recommended treatments.¹¹ It's a major reason, experts suspect, that only about half of all patients take prescribed medications as directed.¹²

In fact, notes an American Medical Association (AMA) committee report on the topic, health literacy correlates more strongly with overall health status than education level or any other socio-demographic variables, including income.³

A More Complex System Makes It Harder

So why has health literacy suddenly become a hot topic in health care? One reason is that medicine and health care are simply more complicated today than they were even 20 years ago, requiring more of the patient.

For instance, that same AMA report notes that 25 years ago

patients with asthma were told to take the drug theophylline. "Today, they're asked to monitor their asthma with a peak flow meter, select and correctly use inhalers, sometimes use tapering dosages of steroids, and avoid triggers that exacerbate their disease," the report says.³ The same might be said of people with diabetes, who often have to test their blood sugar levels several times a day, track the results, and change their insulin injections according to the readings. If you can't read numbers, that's nearly impossible to do.

That's what nurse practitioner and diabetes educator Carmen R. Phaneuf, RN, NP, found with one of her patients. Ms. Phaneuf, who runs the diabetes program for the Parker Family Health Center in Red Bank, NJ, a free clinic for the poor and underinsured, realized the man couldn't read numbers because his glucose readings always ended in a "0." "It didn't make sense," she says. "I had to ask him if he could read and he said 'no.' I told him there was nothing to be embarrassed about."

Yet that's exactly how people feel if they can't read, or can't read well. "We have so much shame," says Ms. Cordell, who graduated high school reading on a fifth grade level. "But we have to step up out of this humiliation if we can, even though that's not easy."

That means taking more control during a health care visit, she says. "Saying, 'What is this paper you're asking me to sign? Could you explain it? Could you explain these words?' That's hard, because you think the person you're talking to is thinking

that you're stupid. I'm not stupid. I just didn't have a good formal education. But it feels like this is my fault, my failure."

Creating Solutions

Tackling the health literacy issue requires a varied approach, the IOM report notes. Everything from writing patient education materials at lower reading levels, to using more pictures in such materials, to teaching health care professionals the best way to communicate complex health information without appearing condescending. Because if there's one thing patients want from their doctor, it's respect.

In fact, a recent *Wall Street Journal Online/Harris Interactive*

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Low health literacy affects people regardless of race, ethnicity, income level and geographic location. Of the 90 million estimated to have problems understanding health information, just 15 percent were born outside the country.

Check and Recheck that Health Information is Understood

Even the simplest health information can easily be misunderstood or acted on incorrectly. This fact underscores the need for health care professionals to check and recheck a client's understanding of medical instructions and for consumers to ask questions about instructions that they don't understand. Consider these real-life examples of health communication gone awry:

- A teenaged girl becomes pregnant because her health care provider told her to take her oral contraceptive every day, but didn't specify she should take it orally. Instead, the girl was inserting the pill in her vagina.
- The mother of a two-year-old diagnosed with an ear infection is told to give her child a teaspoon of an antibiotic twice daily. So she pours a teaspoon of the medicine into her daughter's ears twice a day.²
- A nurse practitioner tells the mother of an infant with diarrhea to stop all formula and give her baby a fortified liquid supplement to avert dehydration to "see if it helps the diarrhea." Five days later, the mother calls back to see if she can now take the baby off the supplement. The nurse is upset that her instructions were unclear and that the baby has spent several days hungry.

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health care poll found that people place more importance on their doctors' interpersonal skills than on their medical judgment or experience. Topping the list: Treating a patient with dignity and respect, listening carefully and being easy to talk to.¹³

To that end, medical schools have begun putting more emphasis on communication issues in their curriculum. Until fairly recently, says Dr. Kripalani, "physicians spent a tremendous amount of energy and education learning how to diagnose and treat an illness, but relatively little attention was given to effectively communicating that information about that illness to patients."

What IS "Clear Communication?"

What does communicating health information clearly really mean? Well, just compare these two explanations from a doctor, each explaining to a patient the lump found in her breast.

VERSION 1: "You have a lesion in your mediastinum that is two centimeters. We need to perform a fine needle aspiration in order to rule out metastatic adenocarcinoma to a lymph node."

VERSION 2: "You have a small lump inside your chest. The way to figure out what it is, is to stick a small needle in it. It is important to do this so we can know how to give you the best treatment."¹⁵

The first explanation is targeted towards someone with an 11th-grade reading level; the second, to someone with a third-grade reading level.

That's slowly beginning to change, according to Deborah Danoff, MD, associate vice president of the division of medical education for the American Association of Medical Colleges. "Health literacy is receiving much more attention since the IOM report came out," she says, with medical schools now beginning to develop resources and teaching opportunities on the

topic. "Until the IOM report, I don't think people were aware of how significant and severe the problem was."

The American Medical Association Foundation, along with pharmaceutical company Pfizer, Inc., are also taking a leadership role in addressing the issue. The two have joined together to raise awareness and understanding of health literacy among health care professionals and to develop tools to improve communication with patients.

That includes the Pfizer Health Literacy Initiative Scholar Awards. Dr. Kripalani uses his, in part, to conduct a regular workshop on clear health communication for internal medicine residents. As part of the training strategy, he videotapes residents with a patient actor, and meets with residents one-on-one to review their communication style. "They are commonly surprised by how much talking they do compared to the patient, and by the language they use," he says. "They're quick to admit their language is too complicated."

So he teaches them to simplify things. To write down instructions, draw simple pictures, use three-dimensional models to explain things, and, above all, be specific. "If the doctor says, 'I want you to get some more aerobic exercise,' what does that mean? How much is more? What does aerobic mean? It's much more effective to say something like, 'I want you to walk around your neighborhood for 30 minutes a day, four days a week, at a pace fast enough to feel your heart beat faster.'"

Most important is the "teach-back" method, in which the health care professional explains

a concept, then has the patient explain it back. "So the doctor might say, 'We talked about a few salty foods you should avoid to control your blood pressure. Tell me two foods you're willing to give up to help your blood pressure,'" says Kripalani.

Communicate in such a way, says literacy advocate Toni Cordell, and health care professionals will gain their patient's undying loyalty. That's how she feels about the urologist who operated on her two years ago. "He talks to me face to face while I'm fully dressed, asks me about my symptoms, gives me clear information. I feel like we're partners in the decision making and that feels really good." ✕

Resources

Center for Health Care Strategies, Inc.
PO Box 3469
Princeton, NJ 08543-3469
609-895-8101
<http://www.chcs.org>
Offers health literacy information and strategies for improving the quality of publicly funded health care.

National Center for Cultural Competence
3307 M Street, NW, Suite 401
Washington, DC 20007-3935
1-800-788-2066
<http://gucchd.georgetown.edu/nccc>
Offers tools for developing culturally and linguistically appropriate health services.

National Council on Patient Information and Education (NCPPIE)
4915 Saint Elmo Avenue, Suite 505
Bethesda, MD 20814-6082
301-656-8565
<http://www.talkaboutrx.org>
Provides information about using medication safely and works to improve health communication.

Partnership for Clear Health Communication
<http://www.askme3.org>
Offers consumer and professional information through the AskMe3 campaign to address low health literacy issues.

Pfizer Clear Health Communication Initiative
<http://www.pfizerhealthliteracy.com>
Provides tools for improving communication in the health care setting.

Providing Culturally Sensitive Health Care

Today, 11 percent of people living in America were born in another country.¹⁶ By 2050, according to some estimates, ethnic minorities will account for 47 percent of the nation's population.¹⁷

No wonder then, that in some areas of the country, hospital signs are written in five or more languages and interpreters are as valuable as a nurse willing to work an extra shift.

Such diversity adds another layer of complexity to interactions between health care professionals and patients. For instance, consider the real-life example of a Native American receiving radiation for cancer. He asks his doctor if he can use the tribal sweat lodge to purify himself. But his Anglo physician recommends against it. The man foregoes the sweat lodge, but feels depressed and spiritually deprived, possibly affecting his overall health and recovery.

“Cultural disparity issues are huge in the health care system,” says Nancy Kressin, PhD, an associate professor in the health services department of Boston University who has a grant from the National Institutes of Health to test interventions designed to increase health care providers' cultural competency. “I don't think we really know the dimensions of it.”

Even defining cultural competency is challenging. Basically, says Dr. Kressin, it means having the health care practitioner develop an awareness and recognition of the ways in which the sociocultural backgrounds of the

patient *and* provider influence the patient's health. “It's the development of clinical practice skills to provide culturally sensitive care.”

For instance, in her work, she finds that different ethnic or cultural groups have different explanations for high blood pressure. African Americans, for instance, are more likely to believe it's related to stress, and that the only way to lower blood pressure is to minimize stress. With that understanding, says Dr. Kressin, culturally appropriate ways could be developed to encourage black patients to take their hypertension medication—even if they have less stress in their lives.

Carmen R. Phaneuf, RN, NP, a nurse practitioner who manages a diabetes program at a family health center in New Jersey, runs up against cultural issues all the time in her practice, where one-third to one-half of her patients are Hispanic. One of her diabetes patients visited a “voodoo doctor” who, he said, “squeezed his pancreas back into place,” curing his diabetes. The man stopped taking his insulin, Ms. Phaneuf says, and by the time she saw him, spiked a blood sugar level of 410.

Misunderstanding a patient's cultural context can be dangerous in other ways. Laurie Scudder, RN-C, PNP, a pediatric nurse practitioner, recalls a student

nurse who examined a Vietnamese child with what looked like long, narrow bruises over her body. The student was ready to call the authorities and report child abuse when a doctor intervened and explained about the Vietnamese custom of “coining,” in which families rub a coin across a child's skin to increase blood flow, sometimes causing bruising. “The family didn't have enough language to explain this practice to the student,” she recalls.

Obviously, few health care professionals have the time to become steeped in the cultural uniqueness of all their patients. And they don't have to, says Dr. Kressin.

She recommends a model developed by Cornell University researchers called ESFT: Explanatory, Social risk, Fears and Concerns, and Therapeutic contracting. Through this process, health care professionals ask patients to explain their illness in their own words, try to understand the social or financial issues that may make it difficult for patients to follow prescribed treatment, ask about patient fears and concerns regarding the treatment, and have the patient use the “teach back” technique described on page 4 to ensure they understood the information.

“By using this approach, providers better understand where each individual patient is coming from,” she says. ✕

Cultural competency means having the health care practitioner develop an awareness and recognition of the ways in which the sociocultural backgrounds of the patient *and* provider influence the patient's health.

Health Literacy & Older Patients

Health literacy affects older adults in disproportionate numbers. Experts estimate that two out of three adults age 60 and over have either inadequate or marginal literacy skills.²

One study of 3,260 new Medicare enrollees found that overall, nearly 34 percent of English-speaking and nearly 54 percent of Spanish-speaking respondents had inadequate or marginal health literacy.¹⁸ And the National Adult Literacy Survey finds that 38 to 49 percent of women over 60 are in the lowest literacy level.¹⁹

“The consequences of low health literacy can be more serious in the elderly,” says Sunil Kripalani, MD, a health literacy researcher at Emory University’s School of Medicine in Atlanta, GA. One reason is that older adults have more chronic conditions than any other age group (about 80 percent of those 65 and older have at least one chronic condition and half have two). Thus, on average, someone with a chronic condition sees eight different physicians on average every year.⁵

That means older patients constantly have to get used to different health care professionals with different communication styles, which, in turn, affects their health. For instance, studies find that older people with health literacy problems are less likely to have ever had a flu vaccine, pneumonia vaccine, or Pap smear, or to have had a mammogram in the last two years.²⁰

“They may also have complex medication regimens, decreased visual acuity, diminished hearing, cognitive decline, physical limita-

tions, live on a fixed income, and have limited access to new means of information retrieval such as the Internet,” says Dr. Kripalani. “It’s really a difficult situation.”

One reason the elderly have more health literacy problems than younger patients may be related to their early education. Census data shows that fewer of today’s older adults finished high school than the general population, with numbers even lower for older ethnic populations.²¹

Also, older people are often not welcomed into the health care system, notes E. Percil Stanford, PhD, who directs western regional operations for the AARP, and who previously directed the University Center on Aging at San Diego State University. “I don’t think we’ve trained health care workers to be aware of the kind of signals they send.” That includes failing to greet patients when they walk into the reception area, talking down to older patients, and addressing older patients by their first name. “A lot of people miss the fact that we’re dealing with older people who are sensitive to being respected,” he says. “Being called by their first name by strangers is degrading.”

In addition to using an older patient’s surname, he suggests health care professionals speak more slowly and loudly to older people, facing them so they can read lips and facial expressions. And because older people often

have vision problems, any instructions should be written out in clear, large handwriting. Additionally, Dr. Stanford suggests medical professionals program more time for visits with older patients than younger ones. Extended office visits are an opportunity for health care professionals to review health information with their older clients, and for older patients to discuss their health concerns and their understanding of any medication instructions.

Because elderly patients are often taking multiple medications, which can be confusing to even those with high health literacy, he recommends limiting the number of medications prescribed whenever possible. “And be sure that someone else, a caregiver or family member, knows what the regimen is,” says Dr. Sanford.

One way older people could increase their health literacy, some experts suggest, is by getting more health information over the Internet. But research finds that many Web sites targeting older adults are written for people with higher literacy levels and better eyesight.²²

To combat that problem, the National Institutes of Health runs its own health-related Web site specifically for older adults: <http://www.nihseniorhealth.gov>. The Web site’s senior-friendly features include large print, short, easy-to-read segments of information and simple navigation. A “talking” function reads the text aloud and special buttons to enlarge the text or turn on high contrast make text more readable. ✕

Ask the Expert: Common Questions About Health Literacy

Q How can I tell if one of my patients has a reading or other health literacy problem?

A You certainly can't evaluate your patients' health literacy based on how they look or talk. Anyone can have trouble understanding what's going on in their health care setting regardless of how educated they are or how well-spoken. And while there are tests available, they're primarily used for research purposes.

But you don't need a test to evaluate your patient's health literacy level. Instead, try to assess your patient's baseline understanding of at least one thing during the visit to provide a brief glimpse into their overall understanding of their health. For instance, if a new diagnosis comes up, like high cholesterol, instead of just launching into an explanation about high cholesterol, pause and say, "What do you already know about high cholesterol?"

Another key opportunity to assess your patient's understanding is through the teach-back method (described on page 4.) If your patient struggles to teach back something you feel you covered pretty clearly, that's a big red flag

that the patient has just been nodding along but didn't really understand what happened in the visit.

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Q My mother who doesn't speak English is being treated for breast cancer. What arrangements can I make to be sure procedure information is translated for her and how does not speaking English affect "informed consent" paperwork?

A The onus for obtaining informed consent is on the health care provider. Consent obtained with the use of materials that the patient or family don't understand is not considered "informed" and thus is not legally defensible. So health care professionals should make sure adequate translation is available. In theory, this means the health care professional must provide the translator. In bigger, more urban medical centers, this is, obviously, easier to do. In smaller places,

family and friends often provide this service on an ad hoc basis.

You should also make sure all your mother's health care professionals know that she is a non-English speaker, and know what her primary language is. Make sure it's documented in her records. Give all health care professionals affiliated with her case phone numbers and any other important contact information for any members of the family or friends who are willing to assist with translation or explanations. Also, assuming your mother is beginning a planned course of treatment, her health care professionals should be able to provide a timeline of treatments and actions.

Those discussions should occur in advance of treatment, in a relaxed setting that allows for questions and truly informs everyone involved, and that allows for the entire family to have some say in the timing of events. If this process occurs, you shouldn't have to worry if you're not available 24/7, because you can anticipate what will occur and when.

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Face-to-Face with Your Health Care Professional

We've talked a lot about all the things health care professionals do wrong when it comes to communicating health information. But what about you? What is your role in the relationship? Well, as with any relationship, health communication is a two-way street.

I know that I rely on my patients to tell me about any confusion they may have, or about things they don't understand, just as much as I rely on them to tell me where it hurts. So, speak up, if you don't understand something. If you have problems reading, tell your doctor or nurse. I promise you: They won't think less of you. Instead, I guarantee they'll try to find you the help you need, and, hopefully, improve the way they communicate with you.

But there is much more you can do. The Partnership for Clear Health Communication has created the *Ask Me 3* program designed to help patients better understand the health information they get from their health care professionals. It works like this:

When you see your health care professional (and don't forget to include your pharmacist and dentist in that group) ask these three questions:

1. What is my main problem?
2. What do I need to do?
3. Why is it important for me to do this?

When a medicine is prescribed or recommended, find out what you need to know and do in order to use your medicine safely. The National

Council on Patient Information and Education (NCPIE) recommends asking:

1. What is the name of the medicine and what is it for?
2. How and when do I take it—and for how long?
3. What foods, drinks, other medicines, dietary supplements, or activities should I avoid while taking this medicine?
4. Are there any side effects, what are they, and what do I do if they occur?
5. Will this medicine work safely with the other prescription and nonprescription medicines (including herbal and dietary supplements) I am taking?

If you still don't understand your condition or the suggested treatment after you've asked these questions, say, "I appreciate all you've told me. But I'm still not clear about . . . Is there another way you could explain it to me?"

There are other things you can do, too. For instance, bring a friend or family member to your medical appointment. Make a list of questions and concerns to ask your doctor or nurse before your visit. Turn to your pharmacist for help when you have questions about your medications. NCPIE also offers comprehensive information to help you use your medication safely. To learn more, visit <http://www.talkaboutrx.org>.

Of course, if you've done everything here and you still can't understand the health information your health care professional is giving you, maybe it's time to find a new one. ✕



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Communicating Online with Health Professionals

Need a prescription refill? Want to let your nurse practitioner know your blood glucose levels? Try e-mailing your health care professional. As a busy physician, I know I find e-mail a convenient way to communicate with my patients about simple issues that don't require an office visit.

Unfortunately, though, studies find less than 10 percent of Americans communicate with their health care professionals via e-mail even though 65 percent of adult Internet users would like to.

If your health care professional is hesitant to use e-mail, explain that studies find it saves health practitioners time, can aid in preventive health care and may even be reimbursable by your insurance company. Also make sure you:

- Only use the providers' e-mail address for legitimate health reasons. Don't forward jokes, add to mass mailing lists, or use it for personal reasons.
- Don't try to substitute e-mail consultations for in-office consultations. You still need to see your health care professional face-to-face.
- Follow any and all e-mail policies your health care professionals' office has set. Many are in place to protect your privacy.
- Let your health care professional know what course of action you plan to take. In other words, finish the feedback "loop."