Health Literacy: Making It Clear

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Our Agenda Today

• Identify components of health literacy, including public health literacy
• Discuss what it means for practitioners to be “health literate”
• Examine the impact of limited health literacy on patient health and health care costs
• Review examples of materials that present barriers to understanding health information
• Review best practices and practical strategies for improving health literacy through clear communication

What Is the New Jersey Health Literacy Coalition (NJHLC)?

• Our mission:
  – A not-for-profit organization committed to improving health outcomes and increasing the efficiency of the health care system through better communication between health care professionals and the diverse communities they serve.
• Our partners and stakeholders include passionate people from:
  – hospitals and clinics
  – federally qualified health centers (FQHCs)
  – public health agencies
  – pharmaceutical and biotech companies
  – health plans
  – universities
  – social service and community-based organizations
  – adult literacy programs
  – corporations

Achieving Better Health Through Clear Communication
Introduction to Health Literacy

Why Does Health Literacy Matter?

“Far too often, ordinary citizens are placed at risk for unsafe care because .. [of] medical jargon and unclear language.”

“The healthcare industry needs to gear up to employ practices that will meet the needs of increasingly diverse patient populations.”

Joint Commission on Accreditation of Healthcare Organizations (JCAHO). Call to action around public policy white paper; “What Did the Doctor Say?” Improving Health Literacy to Protect Patient Safety.” 2007

What Are They Talking About?

- When should I take my medicine?
- What button should I push when I call the clinic to make an appointment?
- What am I saying “yes” to on the consent form?
- What does blood glucose mean?
- Why do I need a mammogram if I’m not sick?
- Can I use a spoon from my kitchen to measure my child’s medicine?
- How can my family eat healthier if I can’t get fresh fruits and vegetables at my neighborhood market?

The bottom line:
- What is my main problem?
- What do I need to do?
- Why is it important for me to do this?
The Cycle of Costly ‘Crisis Care’

- A wide chasm often separates what providers intend to convey in written and oral communication and what patients understand.
- Too many people are hospitalized after being given ambiguous instructions about medications or failing to recognize symptoms of a worsening condition.
- Improved health literacy has the potential to help address issues of health care access, quality, and cost.

Koh, Howard K. et al., "New Federal Policy Initiatives to Boost Health Literacy Can Help the Nation Move Beyond the Cycle of Costly ‘Crisis Care’", Health Affairs, January 2012, published online before print.

Cost of Low Health Literacy to the U.S. Economy

$106-$238 billion annually

Resulting from:
- Medication errors
- Excess hospitalizations
- Longer hospital stays
- More use of emergency services
- Higher level of illness

What Does Literacy Enable Us to Do?

- Develop skills
- Acquire information
- Engage effectively in conducting daily life

What are the Fundamental Literacy Skills for 21st Century?

Could you understand a paragraph written with these words?

- option
- strike
- value
- net
- spot
- time

- exercise
- probability
- present
- negative
- below
- today

- equal
- underlying
- price
- set
- zero
- using
The Mismatch...

- 88% of the country is below the proficient level in health literacy. (National Assessment of Adult Literacy – 2003)
- Over 1,000 studies have demonstrated that most health materials are written at levels of complexity far beyond the reading skills of average high-school graduates.

Some Health Literacy Challenges

Population Changes
- The elderly population is growing
- The number of Americans with limited English proficiency is growing

Health System Complexity
- The number of medications prescribed has increased
- Hospital stays are shorter
- Heavier reliance on forms, written directions
- Greater self-care requirements
- Verbal instructions are often complex, delivered rapidly, and easy to forget in a stressful situation

The National Patient Safety Foundation
Evolving Definitions of Health Literacy

• "The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."


• "Health literacy allows the public and personnel working in all health-related contexts to find, understand, evaluate, communicate and use information. Health literacy is the use of a wide range of skills that improve the ability of people to act on information in order to live healthier lives. These skills include reading, writing, listening, speaking, numeracy, and critical analysis, as well as communication and interaction skills."

  The Calgary Charter on Health Literacy – Sponsored by The Centre for Literacy of Quebec, October, 2008.

Public Health Literacy

"The degree to which individuals and groups can obtain, process, understand, evaluate, and act upon information needed to make public health decisions that benefit the community."

Primary Aims: Engage more stakeholders in public health efforts; address social and environmental determinants of health

A Multidimensional Model of Health Literacy

Health Literacy is a complex determinant of health. In addition to Fundamental Literacy, it includes these domains:

1. **Scientific Literacy** - includes ability to understand and use science and technology, including some awareness of the process of science.

2. **Civic Literacy** – includes ability to become aware of public issues and knowledge that personal behaviors and choices affect others in a larger community and society. Allows individuals and groups to make public health decisions that benefit the community.

3. **Cultural Literacy** – use of collective beliefs, customs, worldview, and social identity in order to interpret and act on health information.


Keep in Mind that Culture Can Determine...

- **Who** is a member of the family
- **What** are the roles of different family members
- **Who** makes family decisions
- **What** are beliefs about child care/elder care and care giving
- **What** is the meaning of illness or disability
- **What** are acceptable health practices (preventive care, non-traditional medicine, etc)
- **What** are attitudes toward health treatment (medical, mental health, dental, end of life care) and health care professionals

In Summary... Health Literacy Is Not

- the same thing as general literacy. A rocket scientist diagnosed with diabetes may have trouble understanding a new and complex self-care routine.
- only about reading. Obtaining, understanding and acting on health information encompasses a range of skills including communication/interaction, writing, numeracy, technology, and critical analysis.
- a static condition. Factors that impact health literacy include our health status, our experiences and knowledge, language skills, aging process, cultural beliefs and values, and emotions.
National Action Plan to Improve Health Literacy
U.S. Department of Health and Human Services
May 2010

Some basic principles:
(1) Everyone has the right to health information that helps them make informed decisions.
(2) Health literacy is part of a person-centered care process and essential to the delivery of cost effective, safe, and high-quality health services.
(3) Since it is impossible to tell by looking who is affected by limited health literacy, a “universal precautions approach” should be adopted. Clear communication should be the basis for every health information exchange.

“Universal Precautions” Means...
➢ We expect that every encounter is at risk for miscommunication.
➢ We create a “shame-free” environment of care.
   • Treat all patients equally
   • Anticipate communication barriers
   • Communicate clearly with everyone
   • Confirm understanding with everyone
   • Proactively work to minimize barriers

Other National Health Literacy Initiatives
• Limited health literacy is not an individual deficit but a systematic problem that should be addressed by ensuring that all healthcare and health information systems are aligned with the needs of the public and with healthcare providers.

Joint Commission
• “What Did the Doctor Say?” Improving Health Literacy to Protect Patient Safety, February 2007
• Advancing Effective Communication, Cultural Competence, and Patient and Family-Centered Care: A Roadmap for Hospitals, August 2010

Agency for Healthcare Quality and Research (AHRQ)
• Health Literacy Curriculum for Pharmacists (2012)
  http://www.ahrq.gov/pharmhealthlit/index.html#pharmlitqi
Impact of Low Health Literacy

Which Patients Are at Risk for Low Health Literacy?

- Anyone in the U.S.
  - Not a function of age, race, education, income or social class
- Ethnic and racial minority groups
  - Disproportionately affected by low health literacy
  - Carry a disproportionate burden of diabetes
- White, native born Americans
  - Comprise the majority of people with low health literacy
- Older patients, recent immigrants, people with chronic diseases and those with low socioeconomic status
  - Especially vulnerable to low health literacy

*“The Health Literacy of America’s Adults: Results From the 2003 National Assessment of Adult Literacy” U.S. Dept. of Education, National Center for Education Statistics, September 2006.*

Why Does Health Literacy Matter?

People with limited health literacy skills are more likely to:

- Report being in poor health
- Participate in negative health behaviors
- Hold health beliefs that interfere with adherence
- Present in later stages of disease
- Be hospitalized/re-hospitalized
- Misunderstand instructions needed for self-care
- Die at an earlier age, and

Are less likely to:

- Engage in preventive behaviors or services (e.g. mammograms, flu shots, A1C tests, retinal eye exams, blood pressure and cholesterol checks)
- Manage a chronic disease

Informal Assessment of Health Literacy Problems

Learn to recognize “red flags” when patients:
• Consistently have “headaches” or chronically “forget” their eyeglasses when asked to perform reading tasks.
• Often say their hands hurt and will fill out paperwork at home.
• Regularly ask family members, friends, or others to read written materials aloud.
• Identify medications by looking at the pills themselves, rather than reading prescription labels.
• Are unable to explain what medications are for and/or when to take their medication.
• Are unable to follow through with lab tests and referrals and frequently miss their medical appointments.
• Take their medication incorrectly.


A Real Life Example

Mr. G, 45, an Hispanic immigrant, native Spanish language speaker, has a job health screening. He is told his pressure is high, and he can’t work until it’s controlled. He is given a beta blocker and diuretic with instructions to take each “once a day”. One week later he comes to the emergency room. His blood pressure is very low and he is dizzy. Doctors can’t figure out the problem. A Spanish speaker asks him how much medicine he took each day. He replies “22”.
Why did this happen??


Informed Consent??

“If at any time I should have an incurable and irreversible injury, disease, or illness judged to be a terminal condition by my attending physician who has personally examined me and has determined that my death is imminent except for death delaying procedures, I direct that such procedures which would only prolong the dying process be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication, sustenance, or the performance of any medical procedure deemed necessary by my attending physician to provide me with comfort care.”
A Proposed Fix

I request that I no longer receive medical care solely to prolong my life upon diagnosis of a terminal, irreversible condition as determined by my physician. However, I do wish to receive medical care to maintain comfort under the direction of my physician.”

Prescription for Confusion

- 8 yr. old with H1N1 influenza received prescription for Tamiflu oral suspension.

- Medication bottle had prepackaged syringe with markings of 30, 45, and 60 mg.

- Label attached by pharmacy specified the dose as ½ teaspoonful twice a day for 5 days

- Complex mathematical equation is required to figure out correct dose
1. How many calories are contained in ½ cup?

2. Is a bigger number better than a smaller one? (Is the answer the same when you’re looking at the fat line and the protein line?)

3. What’s the difference between saturated fat and trans fat?

4. What % of your daily sodium will you get if you eat the whole container?

5. What’s the difference between “saf” fat and “saturated” fat?

6. If you’re on a salt free diet, can you eat this? (Please pass the sodium).

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Strategies for Improving Communication

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Strategies for Improving Understanding through Clear Communication

Keep in mind that....

- Even immediately after leaving their physicians’ offices, patients are able to recall 50% or less of important information just given to them.

- Nearly half of the information retained is incorrect.

- We need to confirm patient understanding at every point along the way.

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The Teach-Back Method

• Teach-back (also known as the “interactive communication loop”) is a way to confirm that
your patient understands your message/information. It confirms that you have explained to
the patient what they need to know in a manner that the patient understands.

• Patient understanding is confirmed when they explain it (teach it back to you) in their own
words or show you by demonstrating what they have been told.

• This is not a test of the patient’s knowledge. This is a test of how well you explained the
concept.

• Make teach-back a “normal” part of the encounter so patient doesn’t feel singled out.
Example: “I do this with next part with all my patients.”

• If patients cannot restate the information correctly, then explain again by using visuals
(pictures, videos, etc.), using simpler words, or seeking assistance from colleagues/staff.
Provide simply written materials for reinforcement.

Examples of Approaches When Using Teach Back

• “I want to be sure that I explained your medication correctly. Please tell me in your own words how you are going to take
this medicine each day when you are at home.”

• “Show me how you will use this inhaler.”

• “We’ve covered a lot today about your diabetes and I want to
make sure I explained things clearly. Can you tell me 3 things
that will help you control your diabetes?”

• “Now that we’ve talked about adding fiber to your diet, what
will you look for the next time you buy cereal?”

Try the Teach-Back Method

1. Start with one patient/client a day. Try the teach back.
2. Write down your reflection of the experience.
3. Include the following questions:
   • How did it go?
   • What would you do differently?
   • Did the patient/customer seem to mind?
   • Did the teach-back uncover any miscommunication?
It’s Harder than You Think to Understand Medications

– A study presented at the 3rd Annual Health Literacy Research Conference in October 2011 found that for 144 patients averaging 6.5 prescriptions, it took 2.6 teach-back tries for the patients to correctly explain how and when to take their medications.

Communicating in “Plain Language”
Examples:
• Avoid – Stay away from; do not use/eat
• Diet – What you eat; your meals
• Dosage – How much medicine you should take
• Hypertension - ??
• Screening - ??
• Negative - ??
• Normal range - ??
• Moderate - ??
• Postpartum - ??
• Precancerous - ??
• Risk factors - ??
• Carbohydrates - ??
• Stable - ??

More Strategies You Can Use
• Use simple language, sometimes referred to as “living room” language instead of medical terminology.

• AA — Avoid acronyms! And be sure to explain what they mean when you do use them.

• Encourage and invite patients/clients to ask questions. You might even say “It’s okay for you to ask me questions.”

• Use open ended questions when discussing information with your patients.

• Limit the amount of information provided to 3-5 key points. REPEAT key points frequently. Focus on the most critical “need to know” information and convey the “need to do” which is what patients want to hear.

More Ways to Make Information Clear

- Give specific directions using concrete terms. Avoid vague statements that require interpretation. Don’t say “You should get some aerobic exercise.”

- Help patients with calculations, measurements, and making sense of numerical information.

- Introduce yourself and explain your role and the roles of your team in the care process.

- Present information in multiple formats (oral, written, visual, video, etc.) to accommodate various learning styles and promote retention.


Additional Strategies

- Prepare commonly asked questions that can be used when patients/clients are reluctant to ask questions. For example, when a pregnant woman says she has no questions, you can say “A lot of women in their (x) month of pregnancy ask about… Is that a question you want me to answer?”

- Assess patients’ baseline understanding before providing extensive information. (Tailor to the patients’ needs).

- Choose your words carefully. In addition to using “plain language”, define new or complicated terms such as “durable medical equipment”, “second hand smoke”, “salmonella”.

Bottom Line….

- Communicate consistently and persistently.
  - Healthcare team members use similar wording (such as “high blood pressure” not “hypertension”).
  - Staff use consistent language whether communicating in person, by phone, in writing or with voice-mail messages.
  - Members of the team call patients regularly to follow up with them about self-care.
  - All staff use the “teach-back technique” to confirm patients’ understanding.
In Conclusion

• Health literacy is a shared responsibility between patients, healthcare consumers and providers.

• We all benefit from information presented in a clear, understandable way regardless of our literacy levels.

• Health literacy enables individuals to make decisions and then take actions that promote and maintain their health and the health of their families.

Health Literacy Resources
“Universal Precautions Toolkit”
http://www.nchealthliteracy.org/toolkit/

Visit these websites to learn more about health literacy

- Health literacy news and resources, including updates about health literacy initiatives in NJ
  www.njhealthliteracy.org

- Health Literacy and Patient Safety: Help Patients Understand

- Helping patients to develop good questions
  http://www.ahrq.gov/questionsaretheanswer

- Information and Tools to Improve Health Literacy and Public Health
  www.cdc.gov/healthliteracy

Selected Health Literacy Resources

