The Role of Health Literacy in Improving Health Communication

Terry Davis, PhD
Professor of Medicine and Pediatrics
LSU Health Sciences Center
Shreveport

September 13, 2017
NML Association Webinar

Why Focus on Health Literacy?

- Health Literacy is increasingly important as health technology, delivery and research are changing rapidly and bringing new communication challenges.
- Nearly 9 of 10 adults have difficulty using health information that is routinely available in healthcare facilities and the media.
- Clinicians and researchers often fail to grasp the wide chasm between what they want to communicate and what patients understand.
- The demands and expectations of patients and research subjects are increasing and health related decisions are becoming more complex.
- Disparities exist in recruitment and trust in clinical trials, and biorepositories among individuals with low SES, low health literacy, minority groups, and those living in rural areas.

America’s Health Rankings 2015; Department of Education National Assessment of Adult Literacy; Koh Health Affairs 2012
Health Literacy: Definition and Impact

Health literacy is the ability to obtain, understand and use health information and services to make informed decisions.

Low health literacy is linked to poor health outcomes.

Low health literacy linked to:
- ↓ understanding of consent for procedures & trials
- ↓ ability to interpret labels and health messages
- ↓ ability to take medication appropriately
- ↓ likelihood of receiving preventive care- delayed diagnoses
- ↓ knowledge, confidence & skills to manage chronic disease
- ↓ physical and mental health status
- ↑ ER use, avoidable hospitalizations, and readmission
- ↑ disease related complications and mortality


NIH View of Health Communication

• We must not blame individuals for not understanding information that has not been made clear them.
• Everyone, no matter how educated, is at risk for misunderstanding health information if the issue is emotionally charged or complex.
• In almost all cases, physicians try and believe they are communicating understandable information.
• Patients may believe they have understood directions or be embarrassed to ask questions
• It is increasingly difficult for people to separate evidence-based health information online from misleading ads and gimmicks.

http://www.nih.gov/clearcommunication/healthliteracy.htm
Communication challenges with patients who speak a language other than English

- 18% in US speak a language other than English at home
- 54 M Latinos in US (2nd only to Mexico)
- 18 M do not speak English well – Health literacy low among this group with limited English Proficiency (LEP)
- 63% of LEP patients understood instructions from a provider who is language-concordant
- 35% understood instructions from an interpreter

Alicia Fernandez, UCSF Plenary presentation, HARC 2016

Literacy Definition (Requirements) Expand With Increasing Demands Of Society

“...at a level needed to function on the job and in society.”

National Literacy Act, 1991; S. White, Project Director NAALS 2016
1st National Assessment of Health Literacy
Assessed skills in clinical, preventive, and navigational tasks

(quantitative literacy)

Intermediate: 53% (33%)
Basic: 22% (33%)
Proficient: 12% (13%)
Below Basic: 14% (22%)

n=19,000 U.S. Adults
Below basic
Hispanic: 41%
Native American: 25%
Adults ≥ 65: 29%


Health Literacy Tasks

152 tasks (28 health-related)

- **Below Basic** Circle date on doctor’s appt. slip
- **Basic** Give 2 reasons a person with no symptoms should get tested for cancer based on a clearly written pamphlet
- **Intermediate** Determine what time to take Rx medicine based on label
- **Proficient** Calculate employee share of health insurance costs using table

67% probability individual can perform task
Red Flags For Limited Literacy
“You Can’t Tell By Looking”

• May say “I forgot my glasses.”
• Incomplete intake forms
• Frequently missed appointments
• Unable to give coherent, sequential history
• Not taking medications correctly
• Asks fewer questions
• Lack of follow-through with referrals


Hidden Problem:
Understanding Food Labels

• You drink this whole bottle of soda. How many grams of total carbohydrates does it contain?

67.5 grams

• 32% answered correctly

• 200 primary care patients
  • 73% private insurance
  • 67% at least some college
  • 78% read ≥ 9th grade
  • 37% math ≥ 9th grade

**Numeracy Problems are Pervasive**

Percentages & probability are challenging for many:

- Approximately **half** of U.S. adults are unable to calculate a tip.

- **20%** of college-educated adults **don’t** know what is a higher risk – 1%, 5%, or 10%

> U.S. adults scored below adults in 23 industrialized nations in numeracy and problem solving – OECD 2013

---

**Improve Risk Communication**

Provide both positive and negative frames.

- “6 in 10 men who have surgery to treat prostate cancer will be impotent. This means 4 in 10 will not.”

Give absolute estimates - not relative.

- Drug X could reduce your risk of breast cancer by 50% (relative)
- Drug X could reduce your 5-year risk from 4% to 2% (absolute)
Key Ways to Improve Health Communication

• Slow down – focus on patient’s “need to know and DO”
• Avoid medical jargon, use living room language
• Attend to patients culture, family
• Use pictures, pamphlets, meds
• Limit information – write brief take home information
• Repeat and summarize information
• ‘Teach back’/’show back’ to confirm understanding
• Be positive and motivating

Health Information: What is patient most focused on?

Bunny or Duck?
Pictures Can be Good Teaching Tools

*Patients may not understand or use measurements*

Evaluating Health Information

*Checklists are Helpful*

- Is the message obvious on the cover, title, and headings?
- Does pamphlet get to the point quickly?
- Are key messages easy to pick out?
- Can readers easily find what they need to know and do?
- **Is information actionable?**
- Is it too much information?
- Is it culturally and language appropriate?
Consider Reading Level

Average education level of US adults ≥ 12th grade
Average reading level ~ 8th grade
Aim materials ≤ 8th

But... reading level is the tip of the iceberg in developing materials

Assess Reading Statistics on Microsoft

- Flesch-Kincaid estimates difficulty of reading form
- Microsoft 2007 & 2010
  - Go to File Tab; select Options
  - Click on Proofing
  - Check “Show Readability Statistics”
- Go to Review Tab
- Select Spelling & Grammar
- Readability results will show after spelling has been checked
Checklist
To help ensure patients can read & understand material

- Is it written in plain language?
- Are consistent terms throughout the form
- Is it written in active (not passive) voice
  - “your signature” vs “signature of patient”
- Is it formatted for reading ease?
- Is it too long, is information manageable or overwhelming?
- What is plan for discussing information with patients?

Patient Education Materials Assessment Tool (PEMAT)

- A systematic method to assess patient education materials and evaluate their understandability and actionability

- **Understandability**: patients of diverse backgrounds and varying levels of health literacy can process and explain key messages.

- **Actionability**: patients can identify what they can do based on the information presented.

**PEMAT-P for print materials** (24 items)

**PEMAT-A/V for audiovisual materials** (17 items) e.g., videos, multimedia materials,

Score items (1=agree, 0= disagree, 1 NA) sum the total points. Divide by total points possible. Multiply by 100 to get a % which will be the score for each the understandability and actionability. The higher the % the better.
Patient Education Materials Assessment Tool
Examples of items

**Understandability - Ask yourself if I were a patient unfamiliar with the subject does the material...**

- make it’s purpose completely evident
- present information in a logical sequence
- use informative headers
- use visual cues (bullets, bolding, boxes, highlighting to draw attention to key points)
- break or chunk information into short sections
- provide a summary

**Actionability - does the material:**

- clearly identify at least 1 action user can take
- break down actions into manageable explicit steps
- explain how to use charts, graphs, tables
- provide tangible tools - menu planners, checklists to help user take action

American College of Physician’s Patient Self-Management Guides:

*A good model to engage people in their health*

**Guides** focused on:

- **Patient** not disease
- ‘Need to know and do’

**Developed with patients and providers in English and Spanish**

Over 5 million distributed nationally
Focus Is On Doing

- ‘You Can Do It’ checklist at end of each chapter
- Concrete examples of successful action plans
- Emphasis on small steps and patient choice

You Can Do It!

It's not about giving everything up. It's about making little changes you can live with. Choose one of these easy ideas, or write down one or two things you will do for the next few weeks. Take charge!

- I will eat breakfast every morning.
- I will eat seconds at dinner.
- I will not “super size” my meals at fast food restaurants.
- I will pack a lunch instead of eating out.
- I will weigh myself once a week.
- I will join a weight loss support group.
- I will ask the waiter not to bring bread to the table.
- I will eat cookies out of the bag.

*“I don’t wait until I’ve gained five pounds. I make a change when I’ve gained just two or three pounds.”*

User-Friendly Does Not Mean “Dumbed Down”

- Adults with high education and income still prefer brief, to-the-point materials.
- Most patients looking for “what I need to know and do.”
- Patients who want more detailed information appreciate links to websites you recommend.
- Websites need to be accurate, easy to navigate and understand.
Hidden Problems With Media-Focused Patient Education

- Often too long (limit to 4-6 minutes)
- Too many “talking heads”
- Organized using medical model not patient-centered (focus on need to know and do)
- Attend to ‘tone’, patient emotions
- Who will show it? Where? Teachable moment
- Animation created through patients’ perspective showing promise.

Little is known about efficacy of using multi-media tools over print media

Helpful Links for Librarians To Improve Health Information *

- MedlinePlus.gov
  - Comprehensive, evidence-based health information written for consumers
  - Tip: focus on the health topic pages that cover more than 1000 diseases and conditions
  - [https://medlineplus.gov/healthliteracy.html](https://medlineplus.gov/healthliteracy.html)
    - Health Literacy has its own health topic page within MedlinePlus
    - Contains links to clinical trials, and provides links to suggested health literacy websites from the NIH, HHS, and the CDC
  - MedlinePlus.gov’s Drugs & Supplements Section
    - Contains a handy consumer guide about all FDA-approved prescription medications, as well as many vitamins and supplements

*Suggested by Rob Logan, Communication Research Scientist, Office of Communication and Public Liaison, National Library of Medicine
Need Help To Plain Language Materials

- Plain Language Medical Dictionary from the University of Michigan – Taubman Health Sciences Library
  

- This work was performed under a subcontract with the University of Illinois at Chicago and made possible by grant N01-LM-6-3503 from National Library of Medicine (NLM) and its contents are solely the responsibility of the authors and do not necessarily represent the official views of the National Library of Medicine. This application is copyright 2014, The Regents of the University of Michigan.

Research Landscape is Changing

- Clinical research is growing - 2.3 million patients a year sign consent forms
- Consenting patients takes an increasing amount of time, preparation, and training
- Today's studies more likely to include multiple sites, data sharing and biospecimens confidentiality concerns
- There is growing regulatory scrutiny
- Funding agencies concerned that patient comprehension is poor

[Image of informed consent diagram]

Gohn E, J of Nursing Scholarship, 2007
What about Research Material?
Many Validated Instruments Fail to Consider Literacy

- Patients may struggle to independently read and answer validated commonly used surveys.
- May have trouble navigating questionnaires.
- Patients may not understand the stems & just check off answers.
- Likert scales are often challenging for those with low literacy especially if Qs vary in intensity or frequency.
- Too many Likert options are overwhelming (limit to 5).
- Avoid yes/no unless followed by a question that validates answer:
  - Do you know what a mammogram is?
  - If yes, can you tell me in your own words what it is.

Health Literacy Bottom Lines

- Plain language health information needs to be accessible, actionable and be developed with input from patients.
- Patients trust primary care providers and librarians appreciate genuine caring, on-going interest and support.
- Regular touch points (face-to-face, phone) improve patient satisfaction & health outcomes.
- Involving family member is helpful.
- Interactive approach invites engagement, problem solving, empowerment and can improve health outcomes.
What’s Health Literacy Bridge to Action?

• How does this talk stimulate your thinking?
• How can librarians help people improve knowledge and confidence in obtaining, understanding and using health information?

Resources
More Health Literacy Links
Suggested by Rob Logan National Library of Medicine

• PubMed Health Literacy
  o Tip: Provides a portal to many reports on health literacy conferences sponsored by federal and state agencies

• Healthfinder.gov
  o Health prevention information written for consumers, patients, and caregivers that is free and quick to access.
  
  o Provided by the Office of Health Promotion and Disease Prevention via the US Department of Health and Human Services

---

Health Literacy Links
Suggested by Rob Logan National Library of Medicine

• Healthmap.org
  o Map-based site via Boston Children's Hospital. Easy to use; gives patients, caregivers, and providers an understand of public health challenges
  o Tracks health outbreaks as they occur globally

• NCI PDQ
  o Patient cancer treatment summaries
  o Used by health providers – may be challenging for others to read but each entry contains a “patient” link that is geared toward consumers
Health Literacy Information


AHRQ Health Literacy https://www.ahrq.gov/professionals/clinicians-providers/resources/health-literacy.html