

The Importance of Recognizing and Addressing Limited Health Literacy*

**Recording of Presentation is available on HealthyTriCounty.com*

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Adult Literacy¹:

- 130 Million Americans of adults, 54% of adults read at less than a 6th grade level and 43 million read below a 3rd grade level.
 - Estimate that getting everyone's literacy up to at least the 6th grade level is likely to cost 2.3 Trillion dollars or 10% of the GDP per year.
 - Has Familial impact on younger generations literacy and future
 - Work ability – link to economic disadvantage
 - Numeracy vs. literacy – major issue of equity

Personal Health Literacy² is the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.

Key determinants of Health Literacy:

- At least two people involved in any discussion– speaker, listener, perhaps others
- Being told the same thing with different words by different people can be confusing
- Speaker's conviction / effort / style have an impact
- Body language can be important or misleading
- Distractions, fear, trust influence effective communication
 - You can be a PhD, be incredibly knowledgeable, and when the word cancer is spoken, you lose everything for the rest of that conversation.
 - Or when you're told that your wife, your husband has a fatal condition, you lose all understanding after that
- It is not totally dependent on education level

Organizational Health Literacy² is the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.

Technological approaches are being used increasingly, so internet access for the community is extremely important.

Impaired/Limited Health Literacy² (LHL) is:

- The failure to understand what is being communicated in a particular healthcare setting

- LHL is NOT totally dependent on education level
- Very common, occurring in a variety of settings
- Related to literacy in general and social determinants of health; pharmacies are important, as are other social services providers

Recognition of LHL is important because³:

- Patients / families need to understand communications in order to participate in their health care decisions and plans
- Ability to carry out instructions depends on understanding
- Improving understanding leads to improved outcomes
- Understanding of current health status, future risks
- Family support, understanding, satisfaction

Costs of LHL:

- Estimated to cost \$106 – 238 BILLION⁴ (in 2007), could now be \$1.6 – 3.6 TRILLION
- Patient frustration and misunderstanding hard to quantify
- Poor health outcomes are measurable, expensive, and wasteful
- Failure to understand discussions may lead patients to stay away from providers

Who pays these costs of LHL?

- Expensive health care in general
- Individuals – poor outcomes, poor understanding
- Health institutions – over-use, readmissions
- Insurers / subscribers – poor outcomes, higher utilization
- Taxpayers and communities (ie, excessive 911 calls)

Who does LHL affect?

- Patients often don't know what they have and are supposed to do -- so then they do nothing
- Any healthcare setting is at risk, especially with forms
- Many patients are reluctant to admit they don't understand, especially minorities or people who don't speak the language
- Dissatisfaction and blame of care providers are common

Health Literacy Universal Precautions⁵: built on the idea of medical universal precautions that you can't tell who, just by looking, might have any condition, i.e. HIV. Same is true for LHL.

- Assume it affects all
- Only 12% of US adults have literacy skills sufficient to fully understand health communications in all settings
- The LHL may be an issue in only certain settings
- Often helpful for a second person to listen and take notes for better understanding after the discussion

People vary in Literacy, Spoken Language, and Education Level

- People vary in how they like to learn and how they best learn / understand – always ask their preferences

- Speaking a foreign language doesn't guarantee literacy
- Must always check "did you get it?"
- Certain situations, esp. stress, can paralyze understanding

Important to use "Plain Language"⁶

- Medical jargon is hard for many to understand
- "Plain language" uses common words, and is often attributed to "4th or 5th grade level", but it's hard for a speaker to know
- **"Don't use 3-syllable words"** - find simpler words
- Current issues of today are important, but health concepts are also crucial to explain

How can an Individual Caregiver address LHL? ⁵

- Recognize the importance of clear and effective communication
- Follow cues for best understanding, read body language
- Avoid "medical jargon" and use pictures and demonstrations
- Utilize the Teach-back Method to assess understanding – put the burden on yourself (did I explain it well?) rather than on the patient (did you understand what I said?)
- Use the "Ask me 3" Approach.⁷ *Almost everyone has trouble remembering more than 3 items, especially when stressed. These questions need answers (even if not vocalized) in all healthcare encounters:*
 - What is my main problem (both in general and today)?
 - What do I need to do?
 - Why is it important for me to do this / these things?
- Example: Breast Exams:
 - "You need to do regular breast self-examinations, looking for lesions, before a cancer has metastasized" vs. "Every woman has the risk of breast cancer, and it's very important to find it early, before it has spread. That's when it's most treatable. My nurse will show you how to do the exam and explain what we're trying to find. I need you to do them each month and let us know right away if you find a new lump."
- More examples of simplifying your speech
 - "Your malignancy has metastasized" vs. "the cancer has spread"
 - "We had to start him on a ventilator due to his pulmonary edema" vs. "Fluid built up in his lungs, so we had to use a breathing machine"
 - "Take it twice a day on an empty stomach" vs. "Take one pill before eating, every morning and every night"
 - "She has severe renal failure" vs. "Her kidneys have stopped working"
 - "He's not responding to therapy" vs. "The medicines aren't working"
- People with limited literacy are often very reluctant to admit it
- Constant fear of "being discovered"
- Can be a VERY important problem related to consent forms
- Affects spoken and written health communication

How can an Institution address LHL?⁸

- Establish an open, shame - free, helpful environment / culture vs. "We've gone over this several times" -- which seems critical

- Repeatedly demonstrate support of EVERY patient
- Watch for cues that a patient is struggling with forms – “Can I help you with that?” vs. “Wow, this sure is taking quite a while”
- Offer (and provide) personal communication helpers
- Provider patience is crucial; never appear exasperated
- The institutional benefits:
 - Patients are more likely to return as instructed if they feel welcomed and supported
 - Better outcomes – patients are more likely to follow instructions
 - Better satisfaction, better word-of-mouth recommendations, and fewer lawsuits
 - Fewer readmissions with their potential fines

Digital Literacy⁹ is the ability to use information and communication technologies to find, evaluate, create, and communicate information, requiring both cognitive and technical skills.

- It is a MAJOR community issue

Digital Health Equity (the “digital divide”):

- Those who have access to the internet, have a device to access it, and knowledge how to use both show digital literacy
- Health information is widely available on the internet (? true)
- Institutions depend on electronic communication with patients
- Is this the newest social determinant of health or is it a new and specific part of education

The challenge to us is develop programs and policies that minimize the differences and optimize the support for improving health literacy.

- Digital Equity Act of 2021 (part of the “Infrastructure Law”)
 - Two 5-year programs to support states to develop programs to limit inequities in broadband access and Grant programs to encourage effective innovation
 - I would encourage that we all push our legislators to be active and supportive of this, because it's something there's the money for it now.
 - [DigitalEquityAct.org](https://www.digitalequityact.org/) for more information
- Social Determinants of Health all relate to Literacy

Telehealth Innovations and Challenges

- Remote encounter programs blossomed during Covid-19
- Telehealth allows access across the miles, for a wide variety of service
- Patients must be digitally literate to access and truly benefit
- Non-verbal understanding may be challenging in both directions
- The Teach-Back Method is especially crucial, but having the resources to utilize it may be quite challenging

Broad band access in the Tri-County is diverse – some areas with 0-10% coverage. There is basic work to be done. The state has \$5.6 billion in Covid-19 relief money available.

Take-home messages:

- Put effort into communicating effectively with everyone
- This doesn't have to take more time, but it improves quality of care, outcomes & satisfaction
- Effective communication does NOT mean just talking louder & slower (don't be condescending)
- Have patients show / tell what they understand & plan to do
- Digital literacy is important for patients – push to improve it!

Questions/Comments:

- We have found that our clients (Palmetto Project) read at a very basic level and that means that they can fill in their names and contact information, but no more than that.
- Through some of the educational work of Charleston Promise Neighborhood, we are looking to build digital access and equity as well.

¹ National Action Plan 2021 – Barbara Bush Foundation for Family Literacy// www.barbarabushfoundation.org

² Healthy People 2030; www.health.gov/healthypeople2030)

³ Center for Health Care Statistics, Fact sheets

⁴ Vernon J et al. 2007; Low Health Literacy: Implications for National Health Policy

⁵ AHRQ toolkit: www.ahrq.gov/health-literacy/improve/precautions/index.html

⁶ Plain Language Thesaurus: <https://stacks.cdc.gov/view/cdc/11500>

⁷ ihi.org

⁸ Farmanova E et al. Jour Health Care Org, Prov & Finan 2018; 55: 1-17

⁹ "Definitions" National Digital Inclusion Alliance

Resources:

- AMA videos on HL AMA Foundation – amafoundation.org (especially www.youtube.com/watch?v=cGtTZ_vxjyA) Excellent for organizations!
- CDC Health Literacy website: <https://www.cdc.gov/healthliteracy/index.html>
- Center for Healthcare Strategies. Fact Sheets 2013 www.chcs.org
- Emergency Broadband Benefit @ Federal Communication Commission (fcc.gov)
- Farmanova E et al. Organizational Health Literacy: Review of Theories, Frameworks, Guides, and Implementation Issues. Journal Health Care Organiz Provis & Fin 2018; 55:1-17
- Health Literacy from A to Z: Practical Ways to Communicate Your Health Message
- Health Literacy Universal Precautions toolkit -- www.ahrq.gov/health-literacy/improve/precautions/index.html
- Healthy People 2030 (www.health.gov/healthypeople2030)
- Institute for Healthcare Improvement: <http://www.ihi.org/resources/Pages/AudioandVideo/WIHIHealthLiteracy.aspx>
- National Action Plan 2021 – Barbara Bush Foundation for Family Literacy <https://www.barbarabushfoundation.org>
- National Center for Education Statistics: <https://nces.ed.gov/naal/>
- National Digital Inclusion Alliance: <https://www.digitalinclusion.org/definitions>

- Plain Language Thesaurus: <https://stacks.cdc.gov/view/cdc/11500/>
- Vernon J *et al.* 2007; Low Health Literacy: Implications for National Health Policy.
https://hsrc.himmelfarb.gwu.edu/cgi/viewcontent.cgi?article=1173&context=sphhs_policy_facpubs