Health literacy – Curricula and measures:

The models we know, the challenges we face

Health and Literacy: Constructing Curriculum for Health-Care Providers
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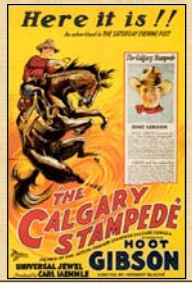


Who's here?

- Interested in building curricula for … ?
  - Health care professionals
    - Clinical
    - Public health
  - ABE/ESOL/ESL
  - General public
  - University courses
  - Medical schools
- Interested in learning about … ?

Things that are difficult to master in a short workshop

- The Tango
- How to make a marriage work
- Health literacy skills for health professionals

What is this thing called health literacy?

This is health literacy

- Yesterday - clip

Health literacy today

- Has come a long way in a short time!
- But … Risks being co-opted into only providing "plain language" materials.

We must expand the practice & discourse of health literacy

- **From** … a primary focus on fundamental literacy in health.

- **To** … a complex social determinant of health and an empowerment model.
- **Address the symptoms <u>and the causes</u>.**

Some of the differences

(Pleasant & Kuruvilla, 2008)

Fundamental literacy in health model	Social determinant/ empowerment model
• Simple screening tools	• Evaluates causes
• Individual focus	• Population focus
• Rewriting as a primary practice	• Seeks system change
• Often focus on clinical encounters	• Seeks to identify social-political causes
• Often blames individuals as lacking	• Health literacy is a problem for all
• Source of most empirical data	• Source of most theories/ conceptual frameworks

but currently …

Alphabet soup of current measures

- **NAAL/ NALS/ IALS** - National Assessment of Adult Literacy and **HLC** (Health literacy component)
- **HALS** - Health Activities Literacy Scale
- **REALM** - Rapid estimate of adult literacy in medicine now REALM Spanish, REALM Teens (really!)
- **TOFHLA, S-TOFHLA, Adapted TOFHLA** - Test of Functional health literacy in adults
- **Newest Vital Sign**
- The **single (or 3) item** screeners
- And … **WRAT** - Wide range achievement test
- And … **SMOG**, **Fry**, **Flesch-Kincaid**, etc.

Initial development samples

- **REALM** N=207; convenience sample; 54% black; 76% female; 42% dropped out of high school
- **TOFHLA** N=403; app. 20% refusal; 11% failed screening; convenience sample, 45% African American “indigent”; 45% Hispanic; 58.5% less than h.s. grad/GED.

Initial development samples

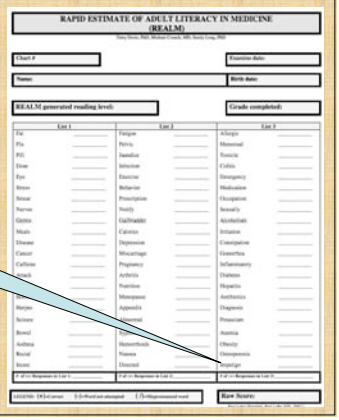
- **NVS** N=500 (250 eng; 250 Spanish); 20% refusal; mean age 41; 21.5% white, 73% Hispanic; 84 men; 416 women.
- **Chew** - N=332; 5% women; 81% white; 86% GED or higher; ambulatory pre-op clinic (excluded ‘worst’ cases like most others)
- **Wallace** N=305; 68% female; 81.3% insured by TennCare/Medicare; only English speaking; 85.2% White; 88% less than H.S. education

Primary audiences - short version

- Black women with less education
- Hispanic and African Americans with less education
- Hispanic women
- White men with GED or higher
- White women with less than high school education

Who's missing??

The REALM



The NVS

2. If you are allowed to eat 60 g of carbohydrates as a snack, how much ice cream could you have?

Answer Any of the following is correct:

- ❑ 1 cup (or any amount up to 1 cup)
- ❑ Half the container

Note: If patient answers "2 servings," ask "How much ice cream would that be if you were to measure it into a bowl?"

- What is health literacy?
- What are the most important questions in this area of health behavior?

Figure 1A. The newest vital sign — English.

Nutrition Facts

Serving Size	1/2 cup
Servings per container	4
Amount per serving	
Calories 250	Fat Cal 120
	%DV
Total Fat 13g	20%
Sat Fat 9g	40%
Cholesterol 28mg	12%
Sodium 55mg	2%
Total Carbohydrate 30g	12%
Dietary Fiber 2g	
Sugars 23g	
Protein 4g	8%

* Percent Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

Ingredients: Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

The TOFHLA: An example

CLINIC APPOINTMENT

CLINIC: Diabetic LOCATION: 3rd floor

DAY: Thurs. DATE: April 2nd HOUR: 10:20 a.m. p.m.

Issued by

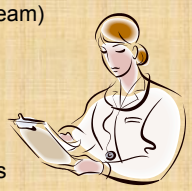
YOU MUST BRING YOUR PLASTIC CARD WITH YOU

PROMPT 5:
When is your next appointment?

Where should you go?

Content of the measures - examples

- Pronouncing medical words
- Navigating a food label (ice cream)
- How often ask for help
- Patient education information
- Prescription bottle labels
- Clinic registration forms
- Instructions for diagnostic tests



Troubles with the TOFHLA: A brief look

- Average refusal + exclusion = 40% (n=48)
- No consistency in reporting (anything)
  - 3 basic versions (in English), but variation exists
  - 18 of 50 articles used 36 point scale; 13 consistently
  - 25 of 50 articles used 100 point scale; 13, 5, 3, 2 consistent in different ways
  - 7 used different scale or didn't report
- No random samples of the general population, meta-analysis population significantly dif. than U.S.
- Ceiling and floor effects
- Mainly one skill (reading) – two at best (numeracy)
- Validity - several biases identified in literature
- Inconsistent treatment - linear or categorical

Any questions or discussion about existing measures of health literacy?

Health literacy curricula - primary audiences

(x indicates some match with existing measures)

- Health care professionals
- University students
- Medical students
- ABE/ESOL/ESL x
- General public x

2 of 5 or 40%

Curricula content - 1

- Lives of immigrants to the U.S. x
- Doctor patient communication x
- Nutrition x
- Clinical practice x
- Medicines x
- Navigation of the health care system x
- Public health
- Poison control
- Geriatric care
- Heart disease
- Chronic disease
- Prevention
- What is and the importance of health literacy

Curricula content - 2

- Diabetes
- Breast Health
- Menopause
- Lead Poisoning
- Household Hazards
- Breast cancer
- Cervical cancer
- Tobacco use
- ABE Professional development
- Children's health
- Pharmacy
- More being produced ….

6 of 24 or 25%

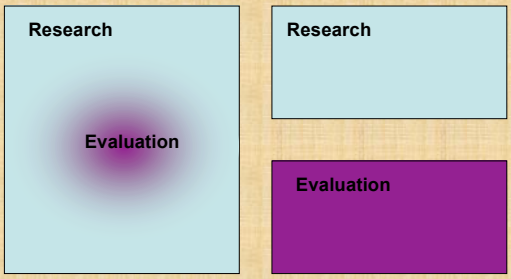
So what?

- Evaluation influences direction of funding, interventions, and policy decisions
- Current measures … Little or no viability for pre-post design
- Ethics of health literacy measurement in clinical settings
- Validation method = Circle the wagons
- No underpinning theory of health literacy
- Little direct utility for informing or evaluating interventions, curricula, policy, or pay for performance

A goal …

- Evaluation should allow for a rigorous tracking of what happened and identify areas of success and failure - **but also why those outcomes occurred.**

An important distinction



However … 1

- Given the contextual nature of health literacy curricula – (diabetes, asthma, etc.)
- Is it possible and useful to create an approach to evaluation that allows comparison across different projects, times, content areas?
- Or must we accept that findings from all the various projects underway will not contribute to a greater whole?
- Who has the resources to take on that challenge?

However … 2

- Establishing formal frameworks might lead to standardized benchmarks and testing.
- This can – but does not have to – create distortions in curricula, the learning process, and resource allocation.
- For example, No Child Left Behind (NCLB) in the United States.

However … 3

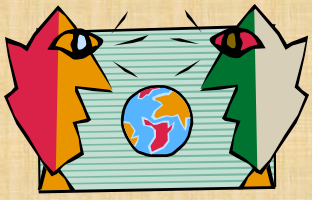
- **IF** performance is tied to a non-funded reward/punishment mandate as in NCLB.
- Only those with resources to assess and address issues revealed can avoid punishment.
- Those least likely to avoid punitive actions generally lack the financial resources to mount corrective actions.
- This can continue and exacerbate existing inequities.

However … 4

- "Even if we could get literacy testing right - which we have not done up to now - there is no way we can test ourselves out of the serious educational problems that afflict our K-12 and adult literacy education systems."

  – Thomas Sticht

Please share your thoughts on the mismatch between existing measures and curricula and challenges of evaluation



How to proceed?

- What do you suggest?

Measurement - A wish list

- Be based on theory/ framework
- Be multi-dimensional (real world contexts)
- Theory & measure should reflect, respond to, or inform:
  - Research agenda (determinants, MDGs)
  - Curricula design
  - Policy needs
  - Intervention design

(DeVillis 1991; Streiner & Norman, 1995)

Wish list … 2

- Treat health literacy as a latent construct
  - Multiple items that **sample** the conceptual domains outlined by theory.
- Respect the principle of compatibility
  - For the attitude-behavior-knowledge relationship to hold true, these must be measured at equivalent levels of action, target, context, and time. (Ajzen, 2005; Ajzen & Fishbein, 2005)
- Commensurate/comparable across contexts (culture, life course, population group, research setting). (DeVillis 1991; Streiner & Norman, 1995)

What we get ..

- A unified approach to health literacy
- A stronger field
- An ability to map out (e.g. structural equation modeling) the "causes of the causes"
- An ability to make explicit the connections between health literacy and health

AND .. Bonus prizes!!!

- An evidence base for the design of curricula, of complex interventions, and of pay for performance metrics.

Suggested approach …

- Agreeing on a consistent testable framework provides basis for a core health literacy measure
- Plus …
  - Developing effective topic specific measures. (E.g., HIV/AIDs, diabetes, etc.)
  - Maintaining comparability
  - 'Swapping out' modules to fit needs and interest
  - Adapting to different contexts/ cultures without necessarily losing commensurability/ comparability
  - Testing, refining, and re-testing theory in a systematic fashion

Suggested approach - don't go it alone!

- Form a broad collaborative effort
  - Enhance content validity
  - Agree on definition
  - Establish consensus on conceptual framework
  - Form working groups aligned with framework and methodology
  - Finalize concept explication
  - Establish guidelines for module creation
  - Generate core item pool - much of this already exists.
  - Test and reduce # of items

Advancing health literacy will require multi-sector partnerships

- Generally, no single sector (or individual) has the range of resources required to launch comprehensive health literacy interventions.
- Therefore, bridging of the various sectors and perspectives on health literacy is needed.
- Focus on active engagement versus passive learning.

The first few (but not only) challenges to collaborating

- Lack of shared vocabulary
  - Patient safety?
  - Quality improvement?
  - Ambulatory care?
  - NAAL?
  - TABE?
  - ABE/ENL/ESL/ESOL?
- Capacity to deliver the 'goods'
- Herding cats

Foot in the door strategies

- Learn a new language - be an adult learner
- Speak up in public
- Ask questions (more than 3)
- Frontal assault via staff
- Frontal assault via board members
- Build a coalition – gain attention, aggregate power
- Find a funder
- Propose a solution versus identify a problem
- Outside expert/ National organization

The opportunities

- Shared goals are in place already!
  - Better health, equity, and health system performance.
- Uniquely complimentary resources
  - You must demonstrate that to people (including yourself)
- The health care system is steadily being told to do it
  - E.g. The Joint Commission; Health Literacy Act 2007
- Adult learners generally want to do it
- The long-term payoffs seem greater than the short-term costs
- It is the right thing to do.

The cautions

- Do not over promise - you don't have to.
- Evaluate – first, last, and always.
- Academic partners can help, but bring baggage.
- Publish or perish – share what you learn.
- Define a sustainability plan.
  - Learning capacity = ability to respond to change

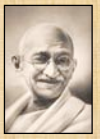
How to proceed? My thoughts …

"Knowing is not enough; we must apply. Willing is not enough; we must do."

-J.W. Goethe

"Hesitating to act because the whole vision might not be achieved, or because others do not yet share it, is an attitude that only hinders progress."

- Mahatma Gandhi



What is a curriculum?

- A body of knowledge to be transmitted
- An attempt to achieve certain ends in students
- A process
- Practical application or exercise of a branch of learning (praxis)

Your view on health literacy will influence your choice of possibilities.

Start here

- Resources available
- Philosophy/ Theory/ Conceptual framework
- Audience & context
- Goal/objectives
- Outcomes

Remember the Golden Rules!

Goals/ objectives

- What are they?
  - What do people possess/ know now?
  - What currently prevents people from reaching the goal?
  - What do they need to reach the goals?
- Then …
  - What will be the outcomes (changes produced) when those goals are reached

How to get from here to there with health literacy

- The wide range of skills and competencies that people develop to **find, understand**, **evaluate**, **use and communicate** health information and concepts to make informed choices, reduce health risks, reduce inequities in health, and increase quality of life in a variety of settings across the life-course.

(Zarcadoolas, Pleasant & Greer, 2003; 2005)
(World Health Organization, 2008)
(Rootman & Gordon-El- Bihbety, 2008)

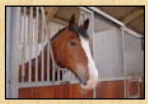
Four domains of health literacy

(Zarcadoolas, Pleasant & Greer, 2003; 2005; 2006)

- **Fundamental**
  - –Reading
  - –Writing
  - –Speaking
  - –Numeracy

Examples … diabetes context

- Your weight is stable since I saw you last month.



- Do you know what the number one cause of people being on dialysis in the country is? Diabetes.
- How have your sugars been running? … That's a wide range.

Scientific

- fundamental health research facts/knowledge
- scientific process
- scientific uncertainty and that rapid change in the accepted science is possible.

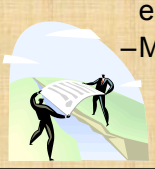
CDC definition of anthrax

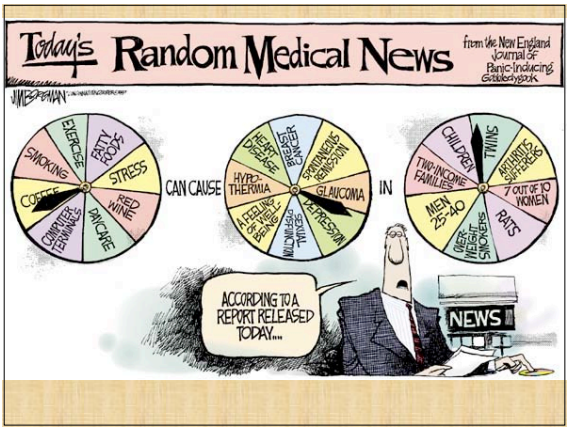
Definition
What is anthrax?
What is the case definition for anthrax?

What is anthrax?
Bacillus anthracis, the etiologic agent of anthrax, is a large, gram-positive, non-motile, spore-forming bacterial rod. The three virulence factors of B. anthracis are edema toxin, lethal toxin and a capsular antigen. Human anthrax has three major clinical forms: cutaneous, inhalation, and gastrointestinal. If left untreated, anthrax in all forms can lead to septicemia and death.

Civic

Tools to navigate power relationships
- Self-efficacy
- Social capital (trust, civic engagement)
- Media literacy





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Cultural

- –Congruence with cultural environment
- –Awareness of different cultural interpretations
- –Ability to communicate and interpret across cultures

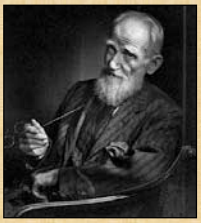
This is health literacy

- Book club story

And remember …

The biggest problem with communication is the illusion that it has occurred.

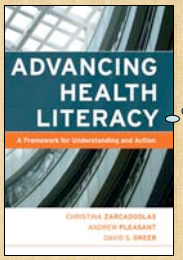
-George Bernard Shaw



Don't believe that?

Think …"Informed" consent

Please share your ideas !!!



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THANK YOU!

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