Measuring Health Literacy

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Outline

Danielle Muscat and Julie Ayre
- Why measure health literacy?
- Measurement tools
- Where to find health literacy tools
- Important considerations

Kim Hobbs
- Experience of measuring health literacy in WSLHD
ACKNOWLEDGEMENT OF COUNTRY

Source: https://www.haikudeck.com/principals-retreat---education-presentation-CBpOV3cCgc
KEEP CALM AND DON'T SHOOT THE MESSENGER
What is health literacy?

- ...the cognitive and social skills that enable individuals to gain access to, understand and use information to make decisions about health\(^1\).

Why Measure Health Literacy?

• Describe a population
• Explore association between health literacy and health outcomes
• Plan and monitor effectiveness of interventions
• Target clinical communication
• Independent contribution to health outcomes (over and above education and literacy)
Which measure should we use?

- **Over a hundred instruments** measuring health literacy in adults have been identified in several systematic and/or scoping reviews.

## Generic vs Specific Measures

<table>
<thead>
<tr>
<th>Specific</th>
<th>Generic</th>
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</thead>
<tbody>
<tr>
<td>Disease specific measures of health literacy.</td>
<td>Measure health literacy across populations and settings.</td>
</tr>
<tr>
<td><strong>For example:</strong></td>
<td><strong>The focus of this presentation</strong></td>
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<tr>
<td>• 6-Item Cancer Health Literacy Test (CHLT-6)</td>
<td></td>
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<tr>
<td>• Literacy Assessment for Diabetes (LAD)</td>
<td></td>
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</tbody>
</table>
# Performance-Based vs Self Reported Measures

<table>
<thead>
<tr>
<th>Performance-based</th>
<th>Self-report</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct test of skills</td>
<td>Self-report of perceived skills</td>
</tr>
<tr>
<td>• More objective</td>
<td>• Often validated against objective instruments</td>
</tr>
<tr>
<td>• Potentially embarrassing</td>
<td>• Some designed for screening rather than measuring health literacy</td>
</tr>
<tr>
<td>• Limited focus on basic numeracy and literacy skills</td>
<td>• Greater potential for response bias</td>
</tr>
</tbody>
</table>
Refresher: Validity and reliability

- Reliability is a measure of the stability or consistency of test scores. You can also think of it as the ability for a test or research findings to be repeatable.

- Validity means that a test or instrument is accurately measuring what it’s supposed to.

Rapid Estimate of Adult Literacy in Medicine (REALM)

- 66 word recognition test
- 1-2 minutes
- verbal task (asks patient to read words aloud)
- not self-administered

<table>
<thead>
<tr>
<th>List 1</th>
<th>List 2</th>
<th>List 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>fat</td>
<td>fatigue</td>
<td>allergic</td>
</tr>
<tr>
<td>flu</td>
<td>pelvic</td>
<td>menstrual</td>
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<tr>
<td>pill</td>
<td>jaundice</td>
<td>testicle</td>
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<tr>
<td>dose</td>
<td>infection</td>
<td>colitis</td>
</tr>
<tr>
<td>eye</td>
<td>exercise</td>
<td>emergency</td>
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<tr>
<td>stress</td>
<td>behavior</td>
<td>medication</td>
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<tr>
<td>smear</td>
<td>prescription</td>
<td>occupation</td>
</tr>
<tr>
<td>nerves</td>
<td>notify</td>
<td>sexually</td>
</tr>
<tr>
<td>germs</td>
<td>gallbladder</td>
<td>alcoholism</td>
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<tr>
<td>meals</td>
<td>calories</td>
<td>irritation</td>
</tr>
<tr>
<td>disease</td>
<td>depression</td>
<td>constipation</td>
</tr>
<tr>
<td>cancer</td>
<td>miscarriage</td>
<td>gonorrhea</td>
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<tr>
<td>caffeine</td>
<td>pregnancy</td>
<td>inflammatory</td>
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<tr>
<td>attack</td>
<td>arthritis</td>
<td>diabetes</td>
</tr>
<tr>
<td>kidney</td>
<td>nutrition</td>
<td>hepatitis</td>
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<tr>
<td>hormones</td>
<td>menopause</td>
<td>antibiotics</td>
</tr>
<tr>
<td>herpes</td>
<td>appendix</td>
<td>diagnosis</td>
</tr>
<tr>
<td>seizure</td>
<td>abnormal</td>
<td>potassium</td>
</tr>
<tr>
<td>bowel</td>
<td>syphilis</td>
<td>anemia</td>
</tr>
<tr>
<td>asthma</td>
<td>hemorrhoids</td>
<td>obesity</td>
</tr>
<tr>
<td>rectal</td>
<td>nausea</td>
<td>osteoporosis</td>
</tr>
<tr>
<td>incest</td>
<td>directed</td>
<td>impetigo</td>
</tr>
</tbody>
</table>

4 categories of scores:
- \( \leq 3^{\text{rd}} \) grade
- 4-6\(^{\text{th}}\) grade
- 7-8\(^{\text{th}}\) grade
- high school

Rapid Estimate of Adult Literacy in Medicine (REALM)

- Administration time
- Established reliability and validity
- Freely available

- Functional health literacy only
- Participant frustration at taking a ‘test’
- Only designed to identify those with reading levels below grade 9
- Only available in English
Test of Functional Health Literacy in Adults (TOFHLA)

Two parts

1) Numeracy

Assesses a patient’s ability to use numerical skills to comprehend directions

Numeracy:
Test of Functional Health Literacy in Adults (TOFHLA) (Parker et al., 1995)

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<tr>
<th>GARFIELD IM</th>
<th>16 Apr 93</th>
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<tbody>
<tr>
<td>FF941862 Dr. LUBIN,</td>
<td>MICHAEL</td>
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<tr>
<td>DOXYCYCLINE</td>
<td>100 mg</td>
</tr>
<tr>
<td>20/0</td>
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</tbody>
</table>

Take medication on empty stomach one hour before or two to three hours after a meal unless otherwise directed by your doctor.

02 11 (0 of 20)

Interviewer: If you eat lunch at 12:00 noon, and you want to take this medicine before lunch, what time should you take it?

Source: Parker et al. JGIM (1995) 10:10
2) Reading comprehension

- Uses a modified cloze procedure, where every fifth to seventh word in a passage is omitted. The reader selects a word to fill in the space from four possible choices.

- Different reading levels: 4th grade level, 10th grade level, and the 19th grade level.
**S-TOFHLA**

- Two reading passages only
- Written task
- Can be self-administered
- Functional health literacy only
- Participant frustration at taking a ‘test’
- License required
- 7 minutes
- 3 categories:
  - Limited
  - Marginal
  - Adequate
- Established reliability and validity (English version)
- Widely used

Newest Vital Sign (NVS)

- 6 questions based on a nutritional (ice-cream) label
- 3-5 minutes

Not self-administered (presented verbally to patient)

3 categories:
- High likelihood of limited literacy
- Possibility of limited literacy
- Adequate literacy

Newest Vital Sign (NVS)

- Established reliability and validity in English
- Administration time
- Freely available

- Functional health literacy only
- Reliability and validity poorer in other languages (Spanish)
- May misclassify patients with adequate health literacy, and overestimate the percentage of patients with limited literacy
- Participant frustration at taking a ‘test’
Chew et al., Screening Questions

1. "How often do you have someone help you read hospital materials?"

2. "How confident are you filling out medical forms by yourself?"

3. "How often do you have problems learning about your medical condition because of difficulty understanding written information?"

Chew et al., Screening Questions

• “How confident are you filling out medical forms by yourself?”

• Possible responses:
  • 0-Extremely
  • 1-Quite a bit
  • 2-Somewhat
  • 3-A little bit
  • 4-Not at all

• Higher scores reflect greater problems with reading
Chew et al., Screening Questions

- < 1 minute
- Self-administered

- Categories
  1. Limited/marginal (corresponds to <9th grade reading level on the REALM)
  2. Adequate
Chew et al., Screening Questions

- Performs reasonably well in detecting “limited/marginal” health literacy.

- Does not perform well in detecting “marginal” health literacy
  - Screener; not designed as a measurement tool
  - May not be sensitive enough to detect change in health literacy or associations with outcomes
Single Item Literacy Screener (SILS)

• "How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?"

• Possible responses:
  • 1-Never
  • 2-Rarely
  • 3-Sometimes
  • 4-Often
  • 5-Always

• Scores greater than 2 indicate some difficulty with reading printed health related material.

Source: Morris et al. BMC Fam Practice (2006) 7:1
Single Item Literacy Screener (SILS)

- < 1 minute
- Self-administered

- 2 Categories
  1. Limited (corresponds to S-TOFHLA limited/marginal categories)
  2. Adequate
Single Item Literacy Screener (SILS)

- Performs reasonably well in detecting limited health literacy.
- Does not perform well in detecting marginal health literacy (sensitivity of 34%)
- Screener; not designed as a measurement tool
- May not be sensitive enough to detect change in health literacy or associations with outcomes
Health Literacy Questionnaire (HLQ)

44-item, self reported measure
Measures health literacy across nine distinct domains:

1. Feel understood and supported by healthcare providers
2. Have sufficient information to manage my health
3. Actively managing health
4. Have social support for health
5. Appraise health information
6. Ability to actively engage with healthcare providers
7. Ability to navigate the healthcare system
8. Ability to find good health information
9. Ability to understand health information well enough to know what to do

Source: https://www.ophelia.net.au/hlq
Health Literacy Questionnaire (HLQ)

- Between 7 to 45 minutes
- Self- or verbally- administered
- Paper and online
- 9 scale scores
Health Literacy Questionnaire (HLQ)

- Multi-dimensional measure of health literacy; goes beyond functional skills
- Can be used to inform health literacy interventions
- Able to detect change in health literacy
- Available in multiple languages
- Used in ABS survey

- License required
- Administration time
Important considerations

- All measures of individual health literacy (can also measure the health literacy of the organisation)

- Problems with validation and ‘gold standards’

- Relationship between language and literacy

- Need to balance burden vs sensitivity

- Similar constructs (patient activation, shared decision making)
Where to find health literacy tools

- Health Literacy Toolshed: https://healthliteracy.bu.edu/
Coming soon: Health Literacy Hub Website

- Health literacy resources (including resources for measuring health literacy)
References


Measuring Health Literacy

Ms Kim Hobbs
Western Sydney Local Health District
Allied Health research project - overview

- Title: *Health literacy among adult patients of allied health at Westmead Hospital: an observational, survey-based study*

- Clinician-led project involving allied health disciplines of: Nutrition and Dietetics, Occupational Therapy, Physiotherapy, Social Work, Speech Pathology

- Two representatives from Faculty of Health Sciences, University of Sydney

- Research expertise provided through the Professorial Unit of WSLHD Research and Education Network
The project team

- Dr Madhan Balasubramanian
- Dr Caron Blumenthal
- Ms Chris Burns
- Ms Dragana Ceprnja
- Prof Sarah Dennis
- Prof Vicki Flood
- Ms Jodi-Anne Gibson
- Ms Rula Milad
- Dr Debra Shirley
- Ms Danielle Stone

- Mr Michael Dunne, Dr Andrew Hirschhorn, Mr Peter Talbot
The HL project – why?

- Many Westmead outpatients demonstrate risk factors for low HL: older age, low level of education, low socioeconomic status, CALD

- Poor HL is associated with poorer management of chronic conditions, more hospitalisations, poorer general health

- Improving HL may reduce health care costs through better compliance with chronic disease management and fewer presentations to hospital and outpatient clinics

- Allied Health is well placed to develop interventions to improve HL
Project aims

- To measure and describe HL of outpatients of Westmead Allied Health departments; using an observational, survey-based study to provide a snapshot of overall HL and its 9 subscales

- To use the survey findings of HLQ and Ophelia methodology to build a body of work to develop, implement and evaluate innovative interventions aimed at improving HL, tailored to the known HL of the sample (Dodson et al, 2017; Beauchamp et al, 2017)

- Future intentions: to initiate practice change informed by evaluation of planned interventions and quality improvement activities
Health literacy Questionnaire (HLQ)

- 44 items, 9 sub-scales scored on four and five point Likert scales (Osborne et al, 2013)

- Translated and back-translated into several community languages. We used Chinese, Arabic and Hindi

- Strong construct validity, strong reliability and unbiased mean estimates of group differences (Osborne et al, 2013)
Health literacy Questionnaire (HLQ)

- Scoring algorithm results in 9 subscale scores of HL to give a ‘health literacy profile’

- Cluster analyses identify groups of individuals with similar HL profiles

- Desired outcome is identification of sub-groups with HL strengths upon which to build; or subgroups with HL limitations, requiring design of services to support
HLQ items – a snapshot

Part 1: indicate how strongly you agree or disagree (4 point scale, 23 items)

– “I compare health information from different sources”

– “I spend quite a lot of time actively managing my health”

– “Despite other things in my life, I make time to be healthy”

– “I have the healthcare providers I need to help me work out what I need to do”
HLQ items – a snapshot

– Part 2: indicate how difficult or easy the following tasks are for you now (5 point scale, 21 items)

– “Work out what the best care is for you”

– “Accurately follow instructions from health care providers”

– “Find out which health care services you are entitled to”

– “Get health information in words you understand”
Health literacy domains

44 items incorporate 4-6 questions per scale

1. Feeling understood and supported by health care providers
2. Having sufficient information to manage my health
3. Actively managing my health
4. Social support for health
5. Appraisal of health information
6. Ability to actively engage with health care providers
7. Navigating the health care system
8. Ability to find good health information
9. Understand health information well enough to know what it is
Why the HLQ?

- Psychometrically sound, validated on an Australian population, making possible comparative analyses. Validated translations

- Multi-dimensional instrument incorporated in 9 scales across the 3 main components of HL: functional, interactive and critical (Nutbeam, 2000)

- An ‘asset-based’ model of HL: strengths based approach with emphasis on improving understanding and capacity to make health related decisions
Why the HLQ?

- Uses cluster analysis to define HL ‘profile’ of the cohort, identifying strengths and limitations

- Enables development (and then evaluation) of ‘fit for purpose’ interventions (e.g., resources, education initiatives) to reduce inequalities in health service access and engagement

- The Ophelia process (OPtimising HEalth LIterAcy) is an accessible methodology for Allied Health clinicians in all health settings
Challenges in using HLQ

- Allow time to sort out the licensing agreement!
- It is a long instrument (44 items plus demographics)
- Paradoxically, completion requires quite high levels of *literacy*
- Benefits from having research assistant personnel to facilitate completion
Limitations of our study

- No access to research assistance resulted in ad hoc participation by clinic patients; not systematic sampling

- Disappointing amount of missing data

- 230 patients recruited were skewed towards a relatively high level of health literacy

- Poor uptake of translated versions of HLQ. Patients with first language of Arabic, Chinese and Hindi usually elected to attempt English language version
Would we do it again?

- Yes, but only with dedicated research assistance.

- In spite of limitations, and relatively high levels of HL in the survey cohort, we did identify some statistically significant differences in some clinics and across some HL domains.

- The range of applications for data collected informs future research directions and has utility for Allied Health clinicians in both hospitals and community health settings.

- The survey was a starting point in the engagement of a collaborative multidisciplinary research team, progressing a body of work that will continue over time.
Final remarks

- Using HLQ to collect baseline data on HL of any given patient population or community is just the first step

- Measurement of HL is not a one-off ‘pass/fail’ exercise

- The value of HLQ data is its capacity to identify differences in what people have (their strengths) and what they need

- Collecting baseline data per se is meaningless without a plan to use that data innovatively to do something different that may empower people to address health problems
Up next: Health literacy and the National Safety and Quality Standards (NSQHS)

- Tuesday 2\textsuperscript{nd} October, 2018
- 2PM – 3PM
- Lecture Theatre 3, WECC
- Level 2, Westmead Hospital