Health Literacy and Medication Awareness in Outpatient Neurology

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Mentored by: Dr. Nabila Dahodwala, MD MS
Agenda

Background
Significance
Questions & Study Design
Hypothesis
Preliminary Results
Limitations
Summary and Next Steps
BACKGROUND
What is “Health Literacy”?

• First used in 1974.

• Capacity to obtain, process, and understand basic* health information and services needed to make appropriate health decisions.
Medical literacy vs. health literacy

• Knowledge, skills, abilities, that pertain to interactions with health care system

• Cognitive/social skills which help individuals to be motivated, informed, and coached for taking care of their health
SIGNIFICANCE
What's the point?

• In 2003¹
  • 30 million American adults had *Below Basic* prose literacy (14%)
  • 27 million had *Below Basic* document literacy (12%)
  • 46 million had *Below Basic* quantitative literacy (22%)

• 35-80% of 65 year olds have inadequate or marginal health literacy.²

• Associated with poorer self reported health, higher hospitalization rates, higher mortality than in age matched controls.³, ⁴, ⁵, ⁶

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Health Literacy in the past

- Relationship of functional health literacy to patients' knowledge of their chronic disease: a study of patients with hypertension and diabetes (Williams et. al, 1998)

- Adherence to combination antiretroviral therapies in HIV patients of low health literacy (Kalichman et. al, 1999)

- Association of health literacy with diabetes outcomes (Schillinger et. al, 2002)
But why now?

- A neurologist’s dictum: “diagnose everything, treat nothing”?

- Select recently FDA approved MS, epilepsy, AD, Parkinson drugs
  - Ampyra (dalfampridine) For the improvement of walking in patients with multiple sclerosis, Approved January 2010
  - Axona (caprylidene); Accera; For the treatment of Alzheimer's disease, Approved March 2009
  - Extavia (Interferon beta-1 b); Novartis; For the treatment of relapsing multiple sclerosis, Approved August of 2009
  - Sabril (vigabatrin); Lundbeck, Inc.; For the treatment of infantile spasms and complex partial seizures, Approved August 2009
  - Stavzor (valproic acid delayed release); Banner Pharmacaps; For the treatment of bipolar manic disorder, seizures and migraine headaches, Approved July 2008
  - Vimpat (lacosamide); Schwarz Pharma; For the treatment of partial-onset seizures in adults with epilepsy, Approved October 2008
  - Amrix (cyclobenzaprine hydrochloride extended release); Cephalon; For the treatment of muscle spasm associated with acute, painful musculoskeletal conditions, Approved February 2007
  - Exelon (rivastigmine tartrate); Novartis; For the treatment of Alzheimer's and Parkinson's disease-related dementia, Approved July 2007
  - Apokyn (apomorphine hydrochloride); Mylan Bertek Pharmaceuticals; For the treatment of acute, intermittent hypomobility episodes associated with advanced Parkinson’s disease, Approved April, 2004

New Anti-epileptic drugs

2009 Conference on new antiepileptic drugs highlights 15 new drugs in the pipeline.

- brivaracetam (ucb 34714),
- carisbamate (RWJ-333369),
- 2-Deoxy-D-glucose,
- eslicarbazepine acetate,
- ganaxolone,
- huperzine A, JZP-4,
- lacosamide,
- NAX-5055,
- propylisopropyl acetamide (PID),
- retigabine,
- T2000,
- tonabersat (SB-220453),
- valrocemide
- YKP3089.
Prevalence in US population

• Neurological conditions are fairly common in the general population:
  • **Stroke** is the third most common cause of death in the US, with **700,000 cases yearly**.  
  
  • Prevalence estimates of **Multiple Sclerosis** in the US range from **6-177 cases per 100,000 people**.
  
  • Nearly **1 percent** of people in the US meeting criteria for **epilepsy** by age 20.

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QUESTIONS AND STUDY DESIGN
Questions

- What is the prevalence of inadequate, marginal, and adequate health literacy in ambulatory neurology patients?

- Can we validate a single screening question as a marker for inadequate health literacy in this population?

- Is health literacy associated with presence of social support systems and self-directed learning behaviors?

- Is health literacy in this population associated with presence of comorbid conditions, medication awareness, and outpatient non-attendance?
Hypothesis

- At least 35% of cognitively intact patients seen in Neurology clinic will have inadequate health literacy. ¹

- Single question can be validated as a screening tool for assessing inadequate health literacy in this population.

Study Design

Cross sectional study
Outpatient Neurology at HUP
Resident Clinic- 2 afternoons/week
Convenience Sample
Role

1) Created Data Dictionary
2) Recruited Patients and administered Survey
   ➢ S-TOFHLA
   ➢ Single Item Test & Interview
   ➢ Chart Review
Patient Population in HUP Neurology Resident Clinic

- Tend to be elderly, on multiple medications, and have frequent contact with healthcare system

- Based on a descriptive study from 2005-2007, common condition treated in clinic:
  - Headaches
  - Epilepsy
  - Neuromuscular
  - Infectious/inflammatory
  - Neurovascular
Inclusion Criteria: Binocular Visual Acuity Test and MMSE

Purpose:

1) Vision Screen to insure ability to read the test that measures health literacy.

2) MMSE to test for cognitive impairment related to dementia.
Single Item Test

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

- Extremely
- Quite a bit
- Somewhat
- A little bit
- Not at all
Interview: Social Support, Comorbidities, and Medications

“Do you have a caretaker at home?”

“Do you have a close friend or family member in the health care field who you talk to about medical questions?”

“What are the names of medications that you take for your neurologic problems?”
3: Test of Functional Health Literacy in Adults: TOFHLA

**Item for Assessment of Numeracy**

Normal blood sugar is 60-150

Your blood sugar today is 160

QUESTION: If this were your score, would your blood sugar be normal today?

**Item for Assessment of Prose Literacy**

Your doctor has sent you to have a _______ x-ray.

a. stomach  
b. diabetes  
c. stitches  
d. germs

You must have an _______ stomach when you come for _______.

a. asthma  
b. empty  
c. incest  
d. anemia

The x-ray will _______ from 1 to 3 _______ to do.

a. take  
b. view  
c. talk  
d. look

a. beds  
b. brains  
c. hours  
d. diets
Chart Review
PRELIMINARY RESULTS
Demographics

- Recruited 40 patients since July 2011.

**Participants by Race (in %)**

- White
- African American/Black
- Hispanic

**Gender of Participants (in %)**

- Male
- Female

**Age Distribution of Participants (in %)**

- 20-29
- 30-39
- 40-49
- 50-59
- 60-69
- 70-79

**Level of Education of Participants**

- Less than High School
- High School Grad
- Some College
- College Grad
- Graduate Degree
## Preliminary Results - Questionnaire

### Self-Confidence Level in filling out medical forms

<table>
<thead>
<tr>
<th>Level</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>1/40</td>
<td>0.025</td>
</tr>
<tr>
<td>A little bit</td>
<td>4/40</td>
<td>0.10</td>
</tr>
<tr>
<td>Somewhat</td>
<td>7/40</td>
<td>0.175</td>
</tr>
<tr>
<td>Quite a bit</td>
<td>10/40</td>
<td>0.25</td>
</tr>
<tr>
<td>Extremely</td>
<td>18/40</td>
<td>0.45</td>
</tr>
</tbody>
</table>

### Caregiver presence at appointment

<table>
<thead>
<tr>
<th>Presence</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Present</td>
<td>10/40</td>
<td>0.25</td>
</tr>
<tr>
<td>Absent</td>
<td>30/40</td>
<td>0.75</td>
</tr>
</tbody>
</table>

### Caregiver presence at appointment

<table>
<thead>
<tr>
<th>Presence</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rarely or never</td>
<td>24/40</td>
<td>0.60</td>
</tr>
<tr>
<td>Less than 50% of the time</td>
<td>8/40</td>
<td>0.20</td>
</tr>
<tr>
<td>More than 50% of the time</td>
<td>8/40</td>
<td>0.20</td>
</tr>
</tbody>
</table>
## S-TOFHLA

<table>
<thead>
<tr>
<th>Health Literacy Level</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inadequate</td>
<td>1/40</td>
<td>0.025</td>
</tr>
<tr>
<td>Marginal</td>
<td>4/40</td>
<td>0.10</td>
</tr>
<tr>
<td>Adequate</td>
<td>35/40</td>
<td>0.875</td>
</tr>
<tr>
<td>Marginal/Inadequate</td>
<td>5/40</td>
<td>.125</td>
</tr>
</tbody>
</table>

**Mean TOFHLA score:** 86.975  
**Minimum TOFHLA score:** 49  
**Maximum TOFHLA score:** 100 (frequency: 7)

### Correlating S-TOFHLA Level and Score

- Inadequate = 0-53 pts
- Marginal= 54-66 pts
- Adequate = 67-100 pts

<table>
<thead>
<tr>
<th>Education Level</th>
<th>Mean TOFHLA score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than high school</td>
<td>74.7</td>
</tr>
<tr>
<td>High school grad</td>
<td>83.4</td>
</tr>
<tr>
<td>Some college</td>
<td>89.8</td>
</tr>
<tr>
<td>College Grad</td>
<td>99.7</td>
</tr>
<tr>
<td>Graduate/professional Degree</td>
<td>94.7</td>
</tr>
<tr>
<td>Male</td>
<td>81.8</td>
</tr>
<tr>
<td>Female</td>
<td>88.3</td>
</tr>
</tbody>
</table>
Single Item Test

Q: How well does the single item predict marginal or inadequate literacy?

<table>
<thead>
<tr>
<th>Criteria 1</th>
<th>Criteria 2</th>
<th>Correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self confidence</td>
<td>TOFHLA scores</td>
<td>0.535</td>
</tr>
</tbody>
</table>

Sensitivity and Specificity

<table>
<thead>
<tr>
<th></th>
<th>“Disease” +</th>
<th>“Disease” -</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Test” +</td>
<td>4 (TP)</td>
<td>1 (FP)</td>
</tr>
<tr>
<td>“Test” -</td>
<td>1 (FN)</td>
<td>34 (TN)</td>
</tr>
</tbody>
</table>

Disease + = "Low TOFHLA" = marginal/inadequate literacy
Disease - = "High TOFHLA" = adequate literacy
Test= "Self Confidence"
Test + = "Low self confidence “not at all; a little bit”
Test - = "High Self confidence “somewhat, quite a bit, extremely”

Sensitivity = 80%
Specificity = 97.1 %
LIMITATIONS
Comparing Participants and Non Participants

Participation rate: 53.5%  [since 7-18-11]
Race of Participants and Non-Participants

- **White**
  - Participants: 0.45
  - Non-participants: 0.42

- **African American/Black**
  - Participants: 0.55
  - Non-participants: 0.52

- **Hispanic**
  - Participants: 0.05
  - Non-participants: 0.08
Participants vs. Non Participants by age

- Participants
- Non-Participants
Characterizing the Non-Participants (cont’d)

• Non participatory males

<table>
<thead>
<tr>
<th>Age range</th>
<th>Number</th>
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</thead>
<tbody>
<tr>
<td>20-30</td>
<td>0</td>
</tr>
<tr>
<td>30-40</td>
<td>0</td>
</tr>
<tr>
<td>40-50</td>
<td>3</td>
</tr>
<tr>
<td>50-60</td>
<td>5</td>
</tr>
<tr>
<td>60-70</td>
<td>1</td>
</tr>
</tbody>
</table>

• Non participatory females

<table>
<thead>
<tr>
<th>Age range</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-30</td>
<td>2</td>
</tr>
<tr>
<td>30-40</td>
<td>3</td>
</tr>
<tr>
<td>40-50</td>
<td>7</td>
</tr>
<tr>
<td>50-60</td>
<td>3</td>
</tr>
<tr>
<td>60-70</td>
<td>2</td>
</tr>
</tbody>
</table>
Non-Participatory Males by Age and Race

- Caucasian: 0.11, 0, 0.33, 0.22, 0.22, 0.11
- African American: 0, 0.22, 0, 0, 0
- Hispanic: 0, 0, 0, 0, 0

Non-Participatory Females by Age and Race

- African American Women: 0.067, 0.067, 0.42, 0.17, 0.17, 0.067
- Caucasian Women: 0, 0.067, 0.067, 0, 0, 0

The graphs show the proportion of non-participatory males and females by age and race.
Summary and next steps
- TOFHLA levels at HUP Neurology are higher than expected.

- No considerable differences between participants and non-participants by age, race, and gender.

- Alter recruitment strategies
  - Different Penn Hospitals
  - By zip code
  - Medicaid only

- Add a control group:
  - Patients with neurological complaints at a primary care setting.
Lessons Learned...

• There is no such thing as having too many statistics/methods oriented classes.

• “Research” is a team endeavor! Time consuming to maintain database, recruit, analyze data on a 1 man team.

• Organization and time management skills must be self implemented and self enforced.

• There is a positive and strong correlation with meeting project goals and friendliness with various administrative staff.
Thank you!

Research Team:
- Dr. Nabila Dahodwala, MD MS
- Dr. Jori Fleisher, MD

SUMR and LDI:
- Joanne Levy
- Lissy Madden
- Megan Pellagrino
- Hoag Levins
- Renee Zawacki

Associated Staff:
- HUP Neurology Administrative Staff