Health Literacy and Numeracy in Diabetes Care: Overview and Insights

Paul Stang, PhD
Vice-President, Janssen R&D
July, 2015
WHAT IS HEALTH LITERACY?

“The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”
- Core: reading and writing
- Associated: speaking, listening, cultural knowledge, and understanding of specific concepts that are necessary to interpret health information (e.g. basic biology).

NUMERACY (quantitative skill) is independently associated with health behaviors and outcomes in diabetes and other contexts

LITERACY IS A COMPLEX SKILL

Literacy

- Cultural and Conceptual Knowledge
- Listening
- Speaking
- Writing
- Reading
- Numeracy
  - Oral Literacy
  - Print Literacy

IOM, Health Literacy, 2004
WHY IS LITERACY IMPORTANT IN HEALTH CARE?

Patients with low literacy may have difficulty:

• Reading prescriptions, following medical instructions
• Understanding educational materials
• Interpreting and applying numbers to health situations
• Consenting to research or procedures
• Answering survey items or other measures
• Following research protocols
WHY IS NUMERACY IMPORTANT IN HEALTH CARE?

Patients with low numeracy may have difficulty:

- Understanding dosages of medications
- Understanding the timing of when to take medications or have them refilled
- Interpreting nutritional information
- Understanding volume status
- Interpreting blood sugars, adjusting insulin
- Understanding risks and probability
### MANY OUTCOMES ASSOCIATED WITH LITERACY

<table>
<thead>
<tr>
<th>Behaviors</th>
<th>Health Outcomes/Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breastfeeding</td>
<td>General health status</td>
</tr>
<tr>
<td>Behavioral problems</td>
<td>Hospitalization</td>
</tr>
<tr>
<td>Adherence to medication</td>
<td>Mortality</td>
</tr>
<tr>
<td>Smoking, substance abuse</td>
<td>Emergency department use</td>
</tr>
<tr>
<td>Knowledge</td>
<td>Depression</td>
</tr>
<tr>
<td>Food label and portion size understanding</td>
<td>Diabetes control</td>
</tr>
<tr>
<td>Birth control knowledge</td>
<td>HIV control</td>
</tr>
<tr>
<td>Emergency department instructions</td>
<td>Prostate cancer stage</td>
</tr>
<tr>
<td>Asthma knowledge</td>
<td>Body mass index</td>
</tr>
<tr>
<td>Hypertension knowledge</td>
<td>Mammography</td>
</tr>
<tr>
<td></td>
<td>Pap smear, STD Screening</td>
</tr>
<tr>
<td></td>
<td>Immunizations</td>
</tr>
<tr>
<td></td>
<td>Cost</td>
</tr>
</tbody>
</table>

DeWalt, JGIM 2004; McCormack, Annals of Internal Medicine 2011
From Rothman: Addressing Health Literacy and Health Communication in Diabetes and Obesity accessed July 1, 2015 from slideplayer.com/slide/4130070/
LITERACY, NUMERACY AND DIABETES

Literacy skills needed:
- Knowledge of disease prevention and disease
- Understanding of educational materials
- Performance of self-management tasks
- Interaction with medical system

Numeracy skills needed:
- Understanding of risk and probability
- Understanding weight status
- Understanding medications
- Understanding nutrition information
- Understanding exercise
- Interpreting glucose and other measures

From Rothman: Addressing Health Literacy and Health Communication in Diabetes and Obesity
accessed July 1, 2015 from slideplayer.com/slide/4130070/
Polling Question

Based on a 2001 study of professional staff at Duke University hospitals, what percentage of the staff passed the basic numeracy scale test?

A. 5% – 9%
B. 15% – 24%
C. 45% - 52%
D. 75% - 88%
NATIONAL ADULT LITERACY SURVEY - 1992

- Survey of 26,000 in the US
- Prose, document and quantitative literacy
- 21-23% of Americans scored in the lowest level of quantitative literacy
- Only 17% of those with graduate degrees or study scored in the highest level of quantitative literacy
- Lipkus, 2001: Study of Professional Staff at Duke University Hospitals
  - Only 15-24% could pass basic test (numeracy scale)
LITERACY AND DIABETES OUTCOMES

![Graph showing glycemic control and health literacy levels.](image)

<table>
<thead>
<tr>
<th>Health Literacy Level</th>
<th>Inadequate (n=156)</th>
<th>Marginal (n=54)</th>
<th>Adequate (n=198)</th>
</tr>
</thead>
</table>

**Glycemic Control**

- First Quartile: HbA\textsubscript{1c} ≤ 7.2%
- Fourth Quartile: HbA\textsubscript{1c} ≥ 9.5%

<table>
<thead>
<tr>
<th>Complication</th>
<th>Study Subjects With Complication, No.</th>
<th>Odds Ratio (95% Confidence Interval)</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Retinopathy</td>
<td>111</td>
<td>2.33 (1.19-4.57)</td>
<td>.01</td>
</tr>
<tr>
<td>Nephropathy</td>
<td>62</td>
<td>1.71 (0.75-3.90)</td>
<td>.20</td>
</tr>
<tr>
<td>Lower extremity amputation</td>
<td>27</td>
<td>2.48 (0.74-8.34)</td>
<td>.14</td>
</tr>
<tr>
<td>Cerebrovascular disease</td>
<td>46</td>
<td>2.71 (1.06-6.97)</td>
<td>.04</td>
</tr>
<tr>
<td>Ischemic heart disease</td>
<td>93</td>
<td>1.73 (0.83-3.60)</td>
<td>.15</td>
</tr>
</tbody>
</table>

*Adjusted for age, sex, race, education, insurance, language, social support, depression, treatment regimen, years with diabetes, and diabetes education, and accounting for clustering of patients within physicians. Hypertension was included in the models for retinopathy and nephropathy; hypertension and smoking were included for all others.

Schillinger, JAMA, 2002
What can we learn from the risk communication research?
Polling Question

A person with an expressive social style would be described as:

A. Prefers to work alone, past oriented, avoids conflict
B. Impulsive, creative, visionary
C. Loyal, avoids change, wants to please
D. Task oriented, likes to be in control, manages change
# TODAY’S PATIENT

Figure 3.1

## The Four Basic Social Styles of Patients

<table>
<thead>
<tr>
<th>Analytical Patient</th>
<th>Driving Patient</th>
<th>Amiable Patient</th>
<th>Expressive Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Task-oriented</td>
<td>Task-oriented</td>
<td>Relationship-oriented</td>
<td>Relationship-oriented</td>
</tr>
<tr>
<td>Prefers to work alone</td>
<td>Likes to be in control</td>
<td>Likes to be member of a group</td>
<td>Likes to stand out in a group</td>
</tr>
<tr>
<td>Slow response; accuracy important</td>
<td>Rapid response; quick decisions</td>
<td>Slower response; wants to please</td>
<td>Rapid, unique response; impulsive</td>
</tr>
<tr>
<td>Likes to organize, solve puzzles</td>
<td>Prefers immediate direct action</td>
<td>Loyal, supportive, empathic</td>
<td>Verbal, humorous, creative</td>
</tr>
<tr>
<td>Likes details, precise measuring</td>
<td>Wants bottom-line results ASAP!</td>
<td>Senses others’ needs and concerns</td>
<td>Dislikes dullness or routine</td>
</tr>
<tr>
<td>Relationships are a lower priority</td>
<td>Not tactful in relationships</td>
<td>Good at on-on-one relationships</td>
<td>Motivating and persuasive</td>
</tr>
<tr>
<td>Past-oriented; likes tradition</td>
<td>Present or future-oriented</td>
<td>Focus on the present</td>
<td>Future focus, visionary</td>
</tr>
<tr>
<td>Dislikes changes; prefers stability</td>
<td>Seeks to manage change</td>
<td>Avoids change; prefers the familiar</td>
<td>Enjoys change; sees opportunity</td>
</tr>
<tr>
<td>Avoids conflict</td>
<td>More authoritarian under stress</td>
<td>Avoids change; prefers the familiar</td>
<td>Uses personal attack in conflict</td>
</tr>
</tbody>
</table>

### Task Focus: Doing and Thinking
- Less responsive
- Controls emotions

### Relationship Focus: Relating and feeling
- More responsive
- Emotes

*Source*: Adapted from Reid and Merrill (1981).
FACTORS THAT INFLUENCE INDIVIDUAL PRECEPTION OF RISK

People tend to believe myths that help them feel that they are not at risk

- Acute myocardial infarction patient: “I’m not at risk for a subsequent event since I’ve been fixed. I’m one of the lucky ones.”

- “I smoke but I don’t eat fat and I exercise, so I won’t get cancer.”

- “I will just smoke for a little while and then I’ll quit (no problem).”
ISSUES IN THE INTERPRETATION OF BENEFIT AND RISK

- Choice of comparator and context
- ‘Framing’
- Thresholds of interest
- Relative vs. absolute data
- Clinically vs. statistically meaningful
- Translating population-level to individual
CONTEXT

• Compared to what?

• The same events may be perceived differently when –
  - Context is changed
  - Different people are exposed to them
  - They *may* occur in the distant future vs. soon

• The average person is a poor intuitive statistician

• Language and numbers are cumbersome

• The media acts as a risk amplifier

• Decision control is often ceded to the healthcare professional
  - However in diabetes, the patient MUST assume control
Polling Question

Which is more likely to lead a patient to consent to angioplasty?

A. ‘99% have no complications’
B. ‘Complications in 1 in 100 patients’
FRAMING
‘99% have no complications’ vs. ‘a risk in 1 in 100’

Which is more likely to lead a patient to consent to angioplasty?

>82%: ‘99% have no complications’

>50%: ‘complications in 1 in 100 patients’

FACTORS IN RISK PERCEPTION:
Consider how they motivate behavior

• Dread (eaten by shark vs. heart attack)
• Control (driving vs. passenger while spouse drives)
• Natural or man-made
• Choice: risk smaller when we choose it
• Children vs. adults
• New vs. existing risk (SARS, west Nile)
• Familiar vs. unfamiliar (polio vaccine 30 years ago vs. now)
• Can it happen to me? (terrorism after 9/11)
• Trust: the lower the trust, the higher the perceived risk
• Catastrophic vs. not
• Equal vs. unequal benefit
META-ANALYSIS OF THE CLINICIAN-PATIENT COMMUNICATION LITERATURE

The consistent message is that patient outcomes are enhanced when the clinician engages the patient comprehensively:

- Gives them information
- Personalizes it to their situation
- Supports them emotionally

(Hall, Roter, Katz, 1988)
THE VISUAL COMMUNICATION OF RISK AND BENEFIT

• People may be wired biologically to learn through visual means (83%)
• Visual information can be processed quickly
• Can present complicated information
• Visual information can also provide context
• Overcomes issues in numeracy, literacy
• We are better at remembering pictures
IS A PICTURE WORTH 1,000 WORDS?

BMI distribution in the Canadian population (2007)

BMI | %
---|---
35+ | 4%
30-34.9 | 13%
25-29.9 | 41%
23-24.9 | 22%
<23 | 20%

Individual risk of diabetes over ten years

35+ | 32%
30-34.9 | 21%
25-29.9 | 10%
23-24.9 | 7%
<23 | 3%

Population burden: new cases 2007 - 2017

| BMI | % | Cases |
---|---|---|
35+ | 4% | 129,280
30-34.9 | 13% | 274,700
25-29.9 | 41% | 418,500
23-24.9 | 22% | 157,800
<23 | 20% | 61,400

“How many Canadians will be diagnosed with diabetes between 2007 and 2017?”
WHICH OF THE FOLLOWING CONVEYS INFORMATION TO MOTIVATE ACTION?
ENDURING MATERIAL IS CRITICAL

- Aim for 8th grade level
- Animations/video have gained great traction with patients in many areas
- Wallet card reminders or guides can be helpful

### What is your asthma control zone?

For each item below, think about the sentence that most closely reflects what you are currently experiencing.

<table>
<thead>
<tr>
<th>Step 1 What to Look for</th>
<th>CONTROLED ASTHMA</th>
<th>UNCONTROLLED ASTHMA</th>
<th>DANGEROUSLY UNCONTROLLED ASTHMA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical activity</td>
<td>Normal</td>
<td>Some interruption</td>
<td>Difficulty breathing</td>
</tr>
<tr>
<td>Reacrier size</td>
<td>Less than 1 week</td>
<td>1-4 weeks</td>
<td>Moderate difficulties</td>
</tr>
<tr>
<td>Daytime symptoms</td>
<td>Less than 4 days</td>
<td>5-7 days</td>
<td>Severe difficulties</td>
</tr>
<tr>
<td>Nighttime symptoms</td>
<td>Less than 1 night</td>
<td>1-3 nights</td>
<td>Intubation required</td>
</tr>
</tbody>
</table>

### Step 2

What is my level of asthma control?

If all check marks are in the green column, your asthma is well controlled (Green Zone).

If you have any check marks in the yellow columns, your asthma is uncontrolled and in the Yellow Zone.

If you have any check marks in the red column, your asthma is dangerously uncontrolled, and you need medical attention.

### Step 3

Steps to Take

Follow your current plan:

- Make an appointment to see your doctor
- Follow the steps below:
  - Seek Immediate Medical Assistance
  - Call 911
  - Take your rescue inhaler as necessary
  - Call healthcare provider if you are not improving within 24 hours

### My Asthma Action Plan

<table>
<thead>
<tr>
<th>My First Aid Guide</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emergency 911</td>
</tr>
<tr>
<td>Phone number:</td>
</tr>
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<td>Phone number:</td>
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### Asthma Control Action Plan

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- Call 911
- Take your rescue inhaler as necessary in 24 hours
- Call healthcare provider if you are not improving within 24 hours
TEACHING CONCEPTS

- Limit advice to key concepts and focus on behaviors and actions
- Focus on one concept at a time; partition information
- Use concrete terms and examples
- Make info culturally relevant and personal
- Avoid jargon!
- Practice patient centered communication and shared goal setting

From Rothman
TEACHBACK TECHNIQUE

New Concept: Health Information, Advice, or Change in Management

Clinician Explains New Concept
Patient Recalls and Comprehends

Adherence

Clinician Assesses Patient Recall and Comprehension

Clinician Clarifies and Tailors Explanation

Clinician Reassesses Patient Recall and Comprehension

Schillinger, Arch Int Med, 2003
SHARE GOAL SETTING

Let patient or family initiate
- Practice reflective listening
- Provide affirmation of positive behaviors
- Show empathy for challenges

Choose goal that is realistic and attainable
- Can offer a few choices and settle on goals together
- Roll with resistance (don’t challenge patients who resist change; instead ask them to come up with solutions)
- Assess their confidence in achieving the goal

Be concrete

Set a time for accomplishing goal
- Let them know it is up to them to make change!
- Promote a “you can do it” approach!
How can visualizations achieve these goals?
141 PATIENTS EXPOSED IN PIVOTAL STUDY TO METFORMIN
>10,000 PATIENTS EXPOSED ACROSS NEWER DIABETES DRUGS: Clinical Development Program

= 100
>1,000,000 NEW USERS OF METFORMIN IN ONE ADMINISTRATIVE CLAIMS DATABASE

= 10000
The trial found that, **on average**, patients on Metformin had larger reductions in fasting plasma glucose than patients on placebo … … but any given patients may not benefit from the drug and some may experience other ‘side’ effects.
What will happen to me when I start Metformin?

The analysis found 100 patients that look like you, and based on their experience, you can expect a 75% chance of benefit …
IN THE END …

We need just understand that there are learnings from the research that should inform how we engage patients

• Personalization … linking behavior with achievement of goals/outcomes

• Not just verbal but enduring material that is clear and directive

• Numeracy is a strong driver that proper graphics can overcome

• Need not MEASURE literacy and NUMERACY but instead use materials that communicate the messages effectively
  - consumer reports
  - examples from Rothman

• I HAVE A PHD in a statistical discipline and I can’t understand most basic numeric representations (e.g. financial)!!!!
CONCLUSION

• Low literacy and numeracy common

• Good literacy and numeracy do not necessarily guarantee success in self-care or ability to understand material

• Patients with lower literacy/numeracy have worse knowledge, behavior, and outcomes

• Interventions that use low literacy materials and improved communication skills can improve outcomes BUT SHOULD NOT BE LIMITED TO THOSE WITH POSSIBLE LOW LITERACY or NUMERACY
Questions?