Past Is Prologue: Future Directions in Health Literacy Research

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Beyond Plain Language
Simplified Polio Vaccine Brochure Improves Comprehension

![Bar chart showing vaccine knowledge (%) by REALM reading grade level.]

- CDC (10th gr)
- LSU (6th gr)

- 0 to 3
- 4 to 6
- 7 to 8
- >= 9

TC Davis. Pediatrics ‘96
Beyond Plain Language

- What can we do to increase the effectiveness of educational materials?
- When are print materials not enough?
- What are the limits of multimedia?
- What is the role of patient narratives?
- Can we teach patients less and activate them more?
Beyond Plain Language

- What can we do to increase the effectiveness of educational materials?
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Conceptual Model of Health Literacy

INDIVIDUAL CAPACITY

Reading Fluency
- Prose
- Quantitative
- Document

Prior Knowledge
- Vocabulary
- Conceptual knowledge of health and healthcare

Complexity and Difficulty of Printed Messages

HEALTH-RELATED PRINT LITERACY
Ability to understand written health information

New Knowledge, Positive Attitudes, Greater Self-Efficacy, Behavior Change

Other Factors:
Culture and Norms
Barriers to change

Improved Health Outcomes

HEALTH-RELATED ORAL LITERACY
Ability to communicate orally about health

Complexity and Difficulty of Spoken Messages

Baker DW, J Gen Intern Med, 2006
Diabetes Knowledge Gained According to Literacy Level

Pre-test score
Post-test score

Similar improvement

Inadequate
Marginal
Adequate

Very low knowledge at baseline

Kandula N, Baker DW, et al. Pt Ed Couns 09
But Large Gap Remains

And gap largest for those with inadequate literacy
Structured Learning

- Low literate often lack prerequisite knowledge required for higher level learning

- To overcome this, we need to:
  - Define learning objectives
  - Analyze learning tasks and define challenges, including background knowledge needed to truly comprehend
  - Design instructional sequence
    - Verbal information, rules, concepts
    - Problem solving

*Principles of Instructional Design. Gagné RM*
Informed Decision
Surgical Treatments have equal survival

Breast cancer starts as a lump in the breast

Parts of the lump can break off and spread to the body

Only this spread through the body kills women with breast cancer

Surgery does not treat cancer that has spread through the body

Your chances of long-term survival with early breast cancer are the same with lumpectomy and XRT and mastectomy

Informed Decision
Beyond Plain Language

• What can we do to increase the effectiveness of educational materials?
• When are print materials not enough?
• What are the limits of multimedia?
• What is the role of patient narratives?
• Can we teach patients less and activate them more?
Quantitative Skills (Numeracy):

Is your blood sugar normal today?

Normal blood sugar is 60 - 150.

Your blood sugar today is 160.

37% Unable to Answer Correctly
Multimedia for Communicating Complex Ideas

- Everyone has sugar in their blood
- It comes from the food you eat: even foods that don’t taste sweet have sugar
- Your body needs sugar to function
- But too much sugar is bad: that’s diabetes
- Your goal is to have just the right amount of sugar: not too much, not too little
Multimedia for Communicating Ideas that Words Alone Cannot Adequately Convey: Deciding Preferences for End of Life Care

“I am going to describe to you an illness called advanced dementia, like advanced Alzheimer dementia, that you may or may not be familiar with. Advanced dementia is an incurable disease of the brain in which one is not able to communicate with others. People with advanced dementia are not able to move around or walk, get out of bed independently, eat by themselves, or communicate understandably with others. People with advanced dementia often have difficulty chewing or swallowing, and require assistance with feeding themselves. Advanced dementia is an incurable disease and most commonly occurs after many years of Alzheimer disease or as the result of strokes. People are not able to answer any questions or tell you about themselves.”

Patient Preferences for Level of Medical Care Before and After Watching Video

Pre-Video Overall Results

- 25 (20.8)
- 22 (18.3)
- 60 (50.0)
- 13 (10.8)

Post-Video Overall Results

- 6 (5.0)
- 18 (15.0)
- 1 (0.8)
- 4 (3.3)
- 16 (13.3)
- 2 (1.7)
- 13 (10.8)

Post-Video Overall Results

- 10 (8.3)
- 107 (89.2)
- 3 (2.5)

Legend:
- Life-Prolonging Care
- Comfort Care
- Limited Care
- Uncertain
Patient Preferences for Level of Medical Care Before and After Watching Video

Pre-Video Overall Results
- 25 (20.8)
- 22 (18.3)
- 60 (50.0)
- 13 (10.8)

Post-Video
- 6 (5.0)
- 18 (15.0)
- 1 (0.8)
- 4 (3.3)
- 16 (13.3)
- 2 (1.7)

Post-Video Overall Results
- 10 (8.3)
- 107 (89.2)
- 3 (2.5)

Legend:
- Dark gray: Life-Prolonging Care
- Light gray: Comfort Care
- Medium gray: Limited Care
- White: Uncertain
Differences in Preferences for Whites, Blacks, and Latinos Diminished Greatly after Watching Video
Beyond Plain Language

- What can we do to increase the effectiveness of educational materials?
- When are print materials not enough?
- **What are the limits of multimedia?**
- What is the role of patient narratives?
- Can we teach patients less and activate them more?
Diabetes Foot Care Module
The Limits of Multimedia

- General concepts or analogies communicated well
- May powerfully change attitudes
- Information goes by very quickly
  - Particularly problematic if low knowledge base
  - Elderly have slower information processing speed
Overcoming the Fast Pace of Multimedia Programs

- “Virtual page turns”
  - Give short segment and stop
  - Viewer can repeat or go forward
  - Medline Plus uses this model
- Combine with print materials
  - “Reverse-engineered” print materials that follow as “companion guide”
- No studies to my knowledge about this
Beyond Plain Language

- What can we do to increase the effectiveness of educational materials?
- When are print materials not enough?
- What are the limits of multimedia?
- What is the role of patient narratives?
- Can we teach patients less and activate them more?
Alternative to the Didactic Model of Behavior Change: A Social Cognitive Approach
Pros and Cons of Patient Narratives Are Unclear

- **Advantages**
  - Role modeling, social learning
  - May powerfully influence attitudes

- **Disadvantages**
  - May not be as successful for education
  - Information goes by quickly
  - Distractors, high “cognitive load”

- **Optimal placement of narratives unclear**
Use Narratives Carefully for Decision Aids

- Systematic review of the effect of narrative information on decision-making
- 17 studies: 41% 1st person, 59% 3rd person
- In 5 of 17 studies, narratives affected decision making, especially if 1st person
- Authors called for caution when using narratives as part of interventions to aid medical decision-making

Beyond Plain Language

- What can we do to increase the effectiveness of educational materials?
- When are words not enough?
- What are the limits of multimedia?
- What is the role of patient narratives?
- Can we teach patients less and activate them more?
Just Do It?

- Traditional model
  - Knowledge, Attitudes, Behavior
- Action model
  - Less information, more goal setting
  - Identify options for behavior change
  - Patient testimonials
Examples of goals set by participants.

I will walk around my block one time 3 days a week.

I will dance with my granddaughter everyday for 10–15 min.

I will bring a healthy snack to work every other day.

I will look into water aerobics classes, and try at least one.

I will eat less fast food by cooking 1 meal a day.

I will read the chapter on eating right.

I will limit the desserts I eat to 2 store-bought sweets a week.

I will take my Lantus™ after work, at least 4 times a week.

To cut back on my drinking to a maximum of 15 drinks [alcoholic beverages] per week.

I will walk or jump 2 times a week for 5 min at 1 p.m.

Talk to a social worker about how I can find a place to live.

Cut in half the amount of bread I eat at breakfast and lunch.

I will talk to my doctor about my depression.

I will ask for a new blood sugar monitor because my old one stopped working.

I will eat a half a candy bar instead of a whole candy bar for my after work snack.

Tuesday and Thursday nights I will eat only one serving of rice with dinner.
Recall and achievement of behavioral goals.

<table>
<thead>
<tr>
<th>Follow-up</th>
<th>Remembered the action plan</th>
<th>Goal achieved and behavior sustained</th>
<th>Goal achieved, behavior not sustained</th>
<th>Goal not achieved, some behavior change</th>
<th>Other behavior change</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 weeks ($n = 240$)</td>
<td>95%</td>
<td>71%</td>
<td>2%</td>
<td>19%</td>
<td>44%</td>
</tr>
<tr>
<td>4 weeks ($n = 232$)</td>
<td>94%</td>
<td>66%</td>
<td>3%</td>
<td>22%</td>
<td>34%</td>
</tr>
<tr>
<td>12 weeks ($n = 229$)</td>
<td>88%</td>
<td>59%</td>
<td>3%</td>
<td>23%</td>
<td>45%</td>
</tr>
<tr>
<td>At all 3 follow-ups</td>
<td>79%</td>
<td>33%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Beyond Teach Back
Learning Mastery Theory

- Benjamin Bloom developed in 1950s
- Postulates that people differ in the speed at which they learn information (i.e., the number of repetitions required)
- Level of mastery is determined by the time devoted to teaching divided by the time required for learning
- Low literate will usually require more repetition of the material to master it
Most Patients Required Multiple Repetitions to Master Informed Consent

Sudore RL, et al. JGIM ‘06
Rate of Mastery Somewhat Higher for Patients with Higher Literacy, but Almost All Need Repetition
Teach Back Successful for Diabetes Education

![Bar chart showing changes in knowledge score for patients in the MDEP TTG group.](chart.png)

- Inadequate/Marginal:
  - Pre-test: 2.7
  - Post-test: 9.1
  - Pass 2: 15.4
  - Pass 3: 16.3
  - Follow-up: 16.8

- Adequate:
  - Pre-test: 5.0
  - Post-test: 5.7
  - Pass 2: 12.3
  - Pass 3: 16.4
  - Follow-up: 16.8

Δ=-11.3†

†The absolute change from TTG pass 3 to follow-up, where the absolute change of the inadequate/marginal group (-11.3) is compared to the absolute change of the adequate group (-8.5); p-value<0.01.
But What About Long-Term Retention?

Table 4. Change in Knowledge Score for Patients in the MDEP + TTG Group

<table>
<thead>
<tr>
<th></th>
<th>Pre-test</th>
<th>Post-test</th>
<th>Pass 2</th>
<th>Pass 3</th>
<th>Follow up</th>
</tr>
</thead>
<tbody>
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<td>Inadequate/Marginal</td>
<td>2.7</td>
<td>9.1</td>
<td>15.4</td>
<td>16.3</td>
<td>∆=-11.3†</td>
</tr>
<tr>
<td>Adequate</td>
<td>5.0</td>
<td>5.7</td>
<td>12.3</td>
<td>16.4</td>
<td>16.8</td>
</tr>
</tbody>
</table>

†The absolute change from TTG pass 3 to follow-up, where the absolute change of the inadequate/marginal group (-11.3) is compared to the absolute change of the adequate group (-8.5); p-value<0.01.
Beyond Teach Back

- How do we improve retention?
- Active learning and problem solving?
- Repetition/reinforcement outside of the healthcare setting?
Beyond the Office
The Status Quo: Most Info Given at Time of Visit

Pre-visit → Visit → Post-visit
A New Paradigm

- Health needs assessed before a visit
- Based on this, patients given materials to prepare them for the discussion.
  - Print, multimedia, or both
  - Standardized information
  - Designed with patients to ensure clarity of words and concepts
- Office tools help providers communicate
- Patients sent home with summaries
- Automatic reminders sent to patients
Before the Appointment

Dear Mr. Lucky,

Thank you for taking the time to complete your health check. This showed that you have never been screened for colon cancer. Screening for colon cancer can save your life.

Please come to your visit 15 minutes early. The nurse will show you a short video and answer your questions. Dr. Quick will also discuss this with you when you see her.
Colorectal Cancer: Screening and Prevention

Understanding Colorectal Cancer

Choosing the Test for You

Stool Cards

Flex Sig

Colonoscopy

Produced by the Center for Communication and Medicine, Division of General Internal Medicine, Northwestern University Feinberg School of Medicine, with funding from the National Cancer Institute (1R21-CA-107242-01A1). Copyright © 2006 – Gregory Makoul PhD and David W. Baker MD, MPH - All rights reserved
<table>
<thead>
<tr>
<th></th>
<th>Stool Cards</th>
<th>Flex Sig</th>
<th>Colonoscopy</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Purpose</strong></td>
<td>Find blood in the stool</td>
<td>See inside rectum and lower part of colon</td>
<td>See inside rectum and all of colon</td>
</tr>
<tr>
<td><strong>Timing</strong></td>
<td>Every year</td>
<td>Every 5 years</td>
<td>Every 10 years</td>
</tr>
<tr>
<td><strong>Location</strong></td>
<td>Home</td>
<td>Doctor's office -or- Hospital</td>
<td>Hospital</td>
</tr>
<tr>
<td><strong>Getting ready</strong></td>
<td>Avoid certain foods and medicines</td>
<td>Use 2-4 enemas the morning of test</td>
<td>Take laxative medicine the night before test</td>
</tr>
<tr>
<td><strong>Things to consider</strong></td>
<td>Not all polyps bleed – can miss some</td>
<td>Not all polyps are in lower part of colon – can miss some</td>
<td>Requires medicine that makes you sleepy</td>
</tr>
<tr>
<td></td>
<td>Not as accurate as other tests</td>
<td>Very small risk of the tube tearing colon (about 1 in 3,000)</td>
<td>Very small risk of the tube tearing colon (about 1 in 1,000)</td>
</tr>
</tbody>
</table>
After the Appointment
Automated Reminders to Reinforce Understanding and Adherence

Dear Mr. Lucky,
I wanted to tell you again how important it is to be screened for colon cancer. Don’t wait! Be sure to schedule your colonoscopy as soon as possible. Remember, this test could save your life.

Sincerely,
Dr. Quick
An Alternative Model

Pre-visit → Visit → Post-visit
Beyond Readability Formulas

or

From Readability To Usability
WELCOME

To your secure personal health management website.

What's New

- Access your After Visit Summaries. View your recent appointments and click on an appointment to review instructions and referrals.
- Caring for a parent or another adult? Proxy Access has been extended to adults age 18 and up.
- Have you been diagnosed with Diabetes? Ask your physician about how you can track your glucose levels with our new flowsheets.
- Protect yourself as Flu season approaches. Click Schedule an Appointment, select Flu Shot, and find a time convenient for you.
- Proxy access is now available for all ages. Find out more on the Proxy Access page.

If you have questions about these enhancements or other functionality, please don't hesitate to contact us via the "Contact Us" feature or our support line at 847.425.3900.
Below are your current medications, their dosage instructions, and the name of the provider who initially ordered each medication. You may request a prescription renewal if you have run out of refills on a prescription.

Flecainide 100 mg PO Tabs

Instructions: Take 1 tab by mouth twice per day.
Prescribed by David Hwang, MD on 5/29/2008

Loratadine (Claritin) 10 mg PO Tabs

Instructions: Take 1 tab by mouth once daily as needed
Prescribed by David Hwang, MD on 5/29/2008

Pralosec 20 mg PO CPDR

Instructions: 1 tablet by mouth twice daily
Prescribed by David Hwang, MD on 5/2/2006

BACK TO THE HOME PAGE
Antiarrhythmic medications for fast heart rates
Example(s): Cordarone, Pacerone (amiodarone), Norpace (disopyramide), Tikosyn (dofetilide), Tambocor (flecainide), (procainamide), Rythmol (propafenone), (quinidine), Betapace (sotalol)

Antiarrhythmic medications for atrial fibrillation
Discusses drugs that help return heart to normal rhythm, maintain it, and reduce heart rate for those in atrial fibrillation. Lists generic and brand names like amiodarone (Cordarone), dofetilide (Tikosyn), and flecainide (Tambocor). Covers side effects.

Heart failure: Avoiding medicines that make symptoms worse
If you have heart failure, you need to be extra careful with medicines. Some can make your heart failure worse. Other medicines may not mix well with your heart failure drugs. This Actionset will help you learn which medicines you may need to avoid and what questions to ask your doctor or pharmacist. Key points Each time y

flecainide
Brand Name(s): Tambocor
How It Works

Antiarrhythmic medicines help return the heart to its normal sinus rhythm, maintain the rhythm after it has been achieved, and/or reduce the heart rate while you are in atrial fibrillation. These medicines stabilize the heart muscle tissue. Antiarrhythmics such as amiodarone or sotalol also slow the heart rate by blocking impulses that pass through the AV node in the heart.

Why It Is Used

Antiarrhythmic medicines are used to convert atrial fibrillation to a normal rhythm. These medicines may be used before electrical cardioversion and may help maintain a normal heart rhythm after successful cardioversion. Ibutilide, another antiarrhythmic, may improve chances of successful cardioversion when used before cardioversion.

How Well It Works

Antiarrhythmic medicines can maintain a normal rhythm in 35% to 75% of the people who use them.¹

Side Effects

Antiarrhythmic medicines may increase the risk of developing a more severe irregular heart rate problem (ventricular tachycardia or ventricular fibrillation). Close monitoring while taking the medicine is important. The risk of side effects is greater with more severe underlying heart disease.
Mommy, you should be on Ibutilide for your atrial fibrillation!
Health Topics
Start here with 800 topics on conditions, diseases and wellness

Drugs & Supplements
About your prescription and over-the-counter medicines, herbs and supplements

Medical Encyclopedia
Includes pictures and diagrams

Dictionary
Spellings and definitions of medical words

News
Current health news and press announcements

Directories
Find doctors, dentists and hospitals

Go Local
A service for finding local resources for health-related issues

Current Health News
- Antibiotics in the ER: It's Often One-Size-Fits All
- Long-Term Back Pain Not Inevitable, Study Finds
- Nutrition Still Not ‘A’ Grade in U.S. Schools
- More news

Featured Site
FLU.GOV
Know what to do about the flu!

In the Spotlight
What's New

Interactive Tutorials
Over 165 slideshows with sound and pictures

ClinicalTrials.gov
Studies for new drugs and treatments

NIH SeniorHealth
Health information for older adults

Surgery Videos
Videos of surgical procedures
Challenges

- How do we demonstrate that patient portals and web sites are problematic for most Americans?
- How can we assess usability of these without direct usability testing, which is time consuming, expensive, and not feasible for all web sites?
- Can we develop general guidelines for how to design these to make them more accessible?
- Can we use online instructional aids or other tools to help increase accessibility and usability?
Use of a Computer Agent to Explain Informed Consent

Computerized “Agent” as Good as Human and Better than Self Study for Comprehension and Satisfaction

<table>
<thead>
<tr>
<th></th>
<th>Agent (N = 9)</th>
<th>Human (N = 9)</th>
<th>Self (N = 11)</th>
<th>Main effect sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comprehension (% correct)</td>
<td>42.20 (20.33)</td>
<td>39.44 (12.86)</td>
<td>25.91 (11.36)</td>
<td>0.006</td>
</tr>
<tr>
<td>Satisfaction (1–7)</td>
<td>6.56 (1.01)</td>
<td>3.89 (2.47)</td>
<td>5.09 (1.70)</td>
<td>0.018</td>
</tr>
<tr>
<td>Likelihood to sign (1–7)</td>
<td>6.21 (1.30)</td>
<td>2.78 (2.39)</td>
<td>3.91 (2.43)</td>
<td>0.011</td>
</tr>
<tr>
<td>Pressure to sign (1–7)</td>
<td>2.11 (2.09)</td>
<td>2.00 (2.00)</td>
<td>1.55 (0.93)</td>
<td>0.719</td>
</tr>
<tr>
<td>Questions asked</td>
<td>1.12 (2.10)</td>
<td>1.22 (2.64)</td>
<td></td>
<td>0.967</td>
</tr>
</tbody>
</table>