Written Materials in the Digital Space

Dan Morrow
Department of Educational Psychology
& The Beckman Institute
University of Illinois, Urbana-Champaign

Funding from NIH; AHRQ
Overview

• Changing ecology of medication information for patients
  • Challenges for cognitive accessibility of information

• Theory-based approach to improving comprehension of online information
  • Cognitive/health literacy resources for comprehension
  • How resources influence comprehension processes
  • Strategies for supporting comprehension processes

• Improving web-based health information for older adults
  • Written information design
  • Multimedia information design (conversational agents)
  • ‘Ecological design’ for online health information (information foraging)
Changing Information Ecology for Patients

FROM PAPER...

Talk to provider (Prescribing)

Take Medication at home

Talk to provider (Pharmacy/Dispensing)

Pick-up Medication (Pharmacy/Dispensing)

Read instructions

**Table: Medication Schedule**

<table>
<thead>
<tr>
<th>Medication</th>
<th>Start</th>
<th>Midday</th>
<th>PM</th>
<th>PM</th>
<th>PM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acetaminophen</td>
<td>1/2</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ibuprofen</td>
<td>1/2</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aspirin</td>
<td>1/2</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cough Syrup</td>
<td>1/2</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decongestant</td>
<td>1/2</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Antihistamine</td>
<td>1/2</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Images:**
- Mixed media images of people, medication, and health information.
- A health brochure or flyer titled "Love Your Health."
Changing Information Ecology for Patients

TO DIGITAL ...

Talk to provider (Prescribing)

Take Medication at home

Talk to provider (Pharmacy/Dispensing)

Pick-up Medication (Pharmacy/Dispensing)
Read instructions
Changing Information Ecology: Challenges for Health Literacy

• New constraints on and affordances for comprehension
  – Access
    • ‘Digital divide’ remains, but cognitive access (find, understand, evaluate, and use information) is more important than technology access.
  – Reading is changing
    • Browsing vs linear reading of (single) documents
    • Managing multiple documents (hyperlinks)
    • Reading in multimedia context (e.g., pervasive graphics)
  – Comprehension requirements
    • Integrating information across multiple documents/info sources
    • Self-regulated learning
      – Monitor/evaluate comprehension (Do I understood this document well enough to move on? Where should I go next? Should I go back to re-read?)
Changing Information Ecology: Challenges for Older Adults

- More likely to have chronic illness that requires self-care (taking medications).

- Increased need to understand and make decisions based on health information..... and thus to negotiate changing ecology of health information (Morrell, 2001; Sharit et al. 2008)

- Greater barriers to cognitive accessibility of information because of age-related changes in literacy and cognitive abilities.
  - Difficulty understanding and evaluating online health information (Czaja et al., 2008; Taha et al. 2013)
Approach to Improving Design of Online Information for Older Adults

1. Identify Cognitive Resources needed for comprehension

2. Analyze how Resources Influence Comprehension Processes

3. Develop Strategies to Improve Comprehension

**Ability/Resource theories**
- Cognitive aging
- Health literacy

**Process theories**
- Comprehension (e.g., language, multimedia)

**Design theories**
- Multimedia
- Human factors (system)
1. Process/Knowledge Model of Health Literacy

(Chin et al. 2011, *J Health Communication*)
Health Literacy and Comprehension

“TAKE 1 TABLET EVERY DAY”

• Word-level processes
  • Recognize words & activate concepts
    WARFARIN; PROFESSIONAL

• Sentence-level processes
  • Integrate concepts into ideas

• Discourse-level processes
  • Elaborate ideas with knowledge into situation model
    (‘bottom line gist’; mental simulation)

P1 (TAKE TABLET)
P2 (QUANTITY: TABLET ONE)
P3 (FREQ: P1 EVERY DAY)
1. Process/Knowledge Model of Health Literacy

- Education
- Age
- Health Status
  - Illness Experience

Processing Capacity: Fluid Ability

Knowledge
- General: Verbal Knowledge
- Specific: Health Knowledge

Health Literacy/Numeracy

Health System Support
- Self Care

(Chin et al. 2011, *J Health Communication*)
1. Process/Knowledge Model of Health Literacy

- Education
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- Processing Capacity: Fluid Ability
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- Self Care

KNOWLEDGE:
- General: Verbal Knowledge
- Specific: Health Knowledge
- Health Literacy/Numeracy

(Chin et al. 2011, J Health Communication)
1. Evidence for Model

- Older adults with lower health literacy recall less self-care information because of lower levels of processing capacity (PC) and knowledge (K).

Chin et al. 2015, *The Gerontologist*
Approach to Improving Design of Online Information for Older Adults

1. Identify Cognitive Resources needed for Self-Care

2. Analyze how Resources Influence Self-care Processes

3. Develop Interventions to Improve Self-care

**Ability/Resource theories**
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2. HL Resources and Comprehension Processes

Summary of Findings

<table>
<thead>
<tr>
<th>Process</th>
<th>Effect of Lower HL Resources</th>
<th>Design Challenges</th>
<th>Digital vs Paper Challenges</th>
</tr>
</thead>
<tbody>
<tr>
<td>Word recognition</td>
<td>Longer, less familiar words recognized less well</td>
<td>Jargon</td>
<td>About same</td>
</tr>
</tbody>
</table>
Helping Older Adults Manage Self-Care: Patient-Centered Approach to Designing Self-Care Information (and Technology)

1. Identify Cognitive Resources needed for Self-Care
2. Analyze how Resources Influence Self-care Processes
3. Develop Interventions to Improve Self-care

**Ability/Resource theories**
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3. Interventions to Improve Self-care: Patient-centered Design of Health Information

- Target HL *resources* (reduce demands on processing capacity; leverage knowledge) to support comprehension *processes* (word recognition, concept integration, knowledge elaboration).

- Multi-faceted approach to redesigning web-based information for self-care of hypertension (HTN) (Chin et al. 2016; *The Gerontologist*)
Typical Passages from the Web

High Blood Pressure: Causes

There are three questions that are asked to determine what underlies your high blood pressure. First, do you have primary or secondary high blood pressure? Second, what causes your blood pressure to be high? Third, what are your risk factors and contributing factors for high blood pressure?

Types of High Blood Pressure

- **Primary Blood Pressure**
  Primary (or essential) high blood pressure is a “rule out condition,” meaning that your healthcare provider diagnoses you with primary high blood pressure when they find no source in your body for your elevated blood pressure. Almost 95% of all high blood pressure is primary. What causes primary high blood pressure is mysterious. The high blood pressure develops gradually over years.

- **Secondary Blood Pressure**
  Secondary high blood pressure results from an underlying condition. It often appears suddenly and causes a rapid elevation in blood pressure. Problems with your kidneys and adrenal glands can lead to secondary high blood pressure. Additionally, you could be born with defective blood vessels, such as coarctation of the aorta, leading to secondary high blood pressure. Finally, many medications can cause high blood pressure, including birth control pills, cold remedies, decongestants, pain relievers, medications that constrict the blood vessels, cocaine and amphetamines.

What causes high blood pressure?

Secondary high blood pressure is caused by a known source like a physiological disease or a medication. Primary high blood pressure has an uncertain cause. The causes of this type, while unknown, are likely to be a complex combination of genetic, environmental, and other factors. Abnormalities in genes for the aldosterone-remminerangiotensin system may cause high blood pressure. Abnormalities in the sympathetic nervous system may also cause high blood pressure.

Who is at risk for high blood pressure?

Though primary high blood pressure has no one cause, many risk factors or contributing factors have been identified:

- **Age and Gender.** As you age, you are more likely to develop high blood pressure, because blood vessels become less flexible. Isolated systolic hypertension (ISH) is the most common form of HBP in older adults. ISH occurs when only systolic blood pressure (the top number) is high. Women after menopause or who are pregnant are also at risk. More children and teens are being diagnosed with high blood pressure due to poor diet and lifestyle.

- **Race and Ethnicity.** High blood pressure tends to start at a younger age among African-Americans. It is often more severe, and causes greater risks for premature death from heart attack, stroke, heart failure, and kidney failure.

- **Family history.** If someone in your family (parents, grandparents, siblings) has high blood pressure, you are more likely to get high blood pressure.

- **Being overweight or obese.** Excess weight increases the strain on the heart due to fatty’s oxygen needs, raises blood cholesterol and triglyceride levels, and lowers HDL (good) cholesterol levels. It can also make diabetes more likely to develop.

- **Not being physically active.** Low physical activity leads to a higher resting heart rate and more pressure. It is also related to obesity, which increases risk of high blood pressure.

- **Tobacco.** Smoking temporarily raises blood pressure and increases your risk of damaged arteries, particularly narrowing artery walls. The use of tobacco can be devastating to your health, especially if you’re already at risk for high blood pressure. Secondhand smoke — exposure to other people’s smoke...
Revising HTN Passages

- Multi-level, comprehensive, approach
  - Guided by our findings, theories (ability/resources, process, design), and recommendations for educating LHL patients (SAM, CDC, NIH...)
  - Interdisciplinary team (medicine, behavioral science, computer science, patients)

<table>
<thead>
<tr>
<th></th>
<th>Reduce PC Demands</th>
<th>Leverage Knowledge</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Content</strong></td>
<td>Include only relevant information</td>
<td>Use familiar concepts</td>
</tr>
</tbody>
</table>

Boudewyns et al., 2015; Pander Maat & Lentz, 2010; Schwartz, Woloshin, & Welch, 2009
Revising Passages

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The Causes and Risk Factors of High Blood Pressure

<table>
<thead>
<tr>
<th>Highlights:</th>
</tr>
</thead>
<tbody>
<tr>
<td>What Causes High Blood Pressure?</td>
</tr>
<tr>
<td>Primary: most common type</td>
</tr>
<tr>
<td>No known cause</td>
</tr>
<tr>
<td>Cannot be cured</td>
</tr>
<tr>
<td>Secondary: uncommon type</td>
</tr>
<tr>
<td>Caused by something specific (like illness or medication)</td>
</tr>
<tr>
<td>Can often be cured</td>
</tr>
<tr>
<td>Some things put you at risk of developing high blood pressure</td>
</tr>
<tr>
<td>What Increases Risk?</td>
</tr>
<tr>
<td>Some risks, you can control</td>
</tr>
<tr>
<td>Some risks, you cannot control</td>
</tr>
<tr>
<td>Can you avoid high blood pressure? Reduce your risk by making lifestyle changes.</td>
</tr>
</tbody>
</table>

High blood pressure (hypertension) usually doesn’t have a known cause but certain things in your life can increase your risk of developing it. To find out if your high blood pressure is being caused by something, your doctor will ask about your medical history, do a physical exam, and test your blood and urine.

What causes my blood pressure to be high?

If your doctor can’t find a cause for your high blood pressure, you have “primary high blood pressure.” This is the most common kind of blood pressure problem. Almost 95% of people with high blood pressure have primary high blood pressure and doctors don’t know what causes it. Primary high blood pressure can’t be cured but it can be treated with medications and changes in your lifestyle.

A very small number of people with high blood pressure have “secondary high blood pressure”. If you have secondary high blood pressure it means that your doctor has found something that is making your blood pressure high. Unlike primary high blood pressure, secondary high blood pressure is always caused by something else. Secondary high blood pressure is uncommon.

Some possible causes of secondary high blood pressure are:

- Problems with your kidneys or adrenal glands
- A birth defect called coarctation of the aorta
- Taking birth control pills, cold medicine, decongestants (like Sudafed), pain relievers (like Advil), migraine headache medications, or amphetamines (like...
Evaluating Revised Passages: Procedure

- 128 older adults (most with HTN; Mean=71 yrs old; High school education or less)

1. Read typical and revised passages at own pace (as on web)
2. Summarized main points of the passage
3. Answered questions (about explicitly presented and inferred concepts)
Evaluating Revised Passages: Results

• Revised passages remembered more accurately
  – 74% versus 70% correct; t(127)=-3.1, p<.01

• Revised passages remembered more efficiently
  – Less effort needed to understand same amount of information (more ‘bang for the cognitive resource buck’)
  – Older adults with more health knowledge benefitted more from the revised passages
Summary of Evaluation Study

• Older adults’ memory for online self-care information improved by comprehensive redesign of passages.
  • Reorganizing content and signaling this organization (advanced organizer, headers) may reduce impact of PC limits on comprehension processes, and help older adults elaborate information with HK to create situation model.
  • May also support self-regulated learning: More efficient in remembering key concepts, which frees resources to evaluate comprehension in the context of online environments (e.g., integrate information across documents).
Beyond Text: Multimedia

• Graphics and other multimedia features are pervasive in online information ecology,

• But potential problems (e.g., distraction, especially for older adults; Griffin & Wright, 2009; Liu et al. 2009; Morrow et al. 2012)....

• As well as potential value!
  – ‘Multimedia principle’ for learning (Mayer 2010)
  – Synergy of mutually reinforcing text and graphics

• Improving gist-based comprehension of numeric risk information in patient portals ....
Collaborative Patient Portals

• Self-care information often provided through patient portals to Electronic Health Records. Older adults are less likely to use portals or to understand portal-based numeric information (e.g., test results).

• Can we leverage multimedia to improve comprehension of test results? Graphics and video provide context for helping to understand the gist of numbers for risk.

• Enhanced formats improve gist comprehension compared to standard format.

• Developing Computer Agent (CA) based on the video to evaluate whether the portal-based CA improves patient comprehension and collaboration with providers.

### Standard Portal Format

<table>
<thead>
<tr>
<th>Component</th>
<th>Your Value</th>
<th>Standard Range</th>
<th>Units</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Cholesterol</td>
<td>184</td>
<td>&lt; 200 -</td>
<td>mg/dl</td>
</tr>
<tr>
<td>Triglycerides</td>
<td>42</td>
<td>&lt; 150 -</td>
<td>mg/dl</td>
</tr>
<tr>
<td>HDL Cholesterol</td>
<td>47</td>
<td>40 - 60</td>
<td>mg/dl</td>
</tr>
<tr>
<td>LDL Cholesterol</td>
<td>130</td>
<td>&lt; 100 -</td>
<td>mg/dl</td>
</tr>
</tbody>
</table>

![Gist comprehension of risk level](chart.png)
Beyond Single Documents: Ecological Design to Support Search and Comprehension

- From animal foraging to information foraging (Fu & Pirolli; 2007; Pirolli & Card, 1999)
- When reading online, how do we decide when to ‘leave the patch’ (text or graphic), where to go next, and how to integrate across these ‘patches of information’?
- Older adults tend to stay longer than younger adults in a text when searching for information before going to another text, yet they remember less information overall (across sources; Chin et al. 2015)
- Older and younger adults can be ‘nudged’ to persevere in reading a text by increasing the effort involved in switching (e.g., longer web page loading time), and they better remember that text (Liu et al., 2016).

Suggests the value of prompting readers to evaluate their understanding of current text as well as their decision to ‘leave the patch’, by using questions or summaries.
Summary: Patient-Centered Approach to Improving Self-Care

1. Identify Cognitive Resources needed for Self-Care
2. Analyze how Resources Influence Self-care Process
3. Develop Interventions to Improve Self-care

P-K Model of HL:
Processing capacity constraints and knowledge gains are important components of health literacy
Summary: Patient-Centered Approach to Improving Self-Care

1. Identify Cognitive Resources needed for Self-Care

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PC and knowledge limits impair comprehension processes at word (recognition), sentence (concept integration), and discourse (knowledge elaboration of text) levels, as well as numeric comprehension processes.
Summary: Patient-Centered Approach to Improving Self-Care

1. Identify Cognitive Resources needed for Self-Care
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Comprehensive redesign of web information improves memory for information available on patient education websites. Adding multimedia context to numbers improves memory for gist-level risk information associated with portal-based lab results.
Collaborators

Elizabeth Stine-Morrow (Educational Psych, UIUC)
Michael Murray (School of Pharmacy, Purdue)
James Graumlich (School of Medicine, UIC-Peoria)
Mark Hasegawa-Johnson (Elect & Computer Engineering, UIUC)
Thomas Huang (ECE, UIUC)
Jessie Chin (Dept of Systems Design Engineering, Univ of Waterloo)
Elise Duwe (MD/PhD program, UIUC)
Darcie Moeller (MD program, Quinnipiac CT)
Anna Madison (Psych, UIUC)