What is health literacy?

“The degree to which individuals have the capacity to obtain, process, and understand health information and services in order to make appropriate health decisions.”

National Academy of Medicine, 2004
What is health literacy?

An intersection of communication factors that affect health
Examples of health literacy in action

Understanding and taking medicine on schedule

Explaining a new health diagnosis and care instructions

Making intake forms easy to read and fill out
Skills mismatch

- Most people read at a 4th—5th grade level, but health education materials are often written at an 11th grade level

- Only 5% of health education materials are written at or below the 6th grade reading level
Years of education required to comprehend

- Goodnight Moon
- JK Rowling (HP 1)
- Hunter S. Thompson
- Stephen King
- Ayn Rand
- JK Rowling (HP 7)
- Sheryl Sandberg
- Tom Clancy
- John Grisham
- F. Scott Fitzgerald
- Hillary Clinton
- David Foster Wallace
- "Academic paper about chess"
- "Affordable Care Act"

Adapted from Snow, 2015
There's no easy way to tell you this, Mr. Harris. You have pseudopseudohypoparathyroidism.*

* A real condition!

It's harmless, it's just not easy to say.
Skills mismatch

- 98% understood “vomit”
- 35% understood “orally”
- 18% understood “malignant”
- 13% understood “terminal”
Skills mismatch

The system has static patient and provider roles

The system is not set up to serve the most vulnerable
Low health literacy leads to poor health

- Worse overall health status
- More emergency room visits
- More hospitalizations
- Higher mortality rates

Griffey et al., 2014; Mitchel et al., 2012; Baker et al., 2007
Disparities in cancer care

Racial, ethnic, and socioeconomic disparities exist in:
- Cancer incidence rates
- Stage distributions
- Survival rates
- Mortality rates

Factors that contribute to disparities:
- Differences in access to high-quality health care
- Social inequalities that influence health behavior
- Attitudes, beliefs, and low health literacy can result in poor health decisions
Universal Precautions for health communication

Use clear communication strategies with *everyone*
10 attributes of a health literate organization

1. Leadership promotes
2. Plans, evaluates, and improves
3. Prepares workforce
4. Ensures easy access
5. Communicates effectively
6. Explains coverage and costs
7. Targets high risk
8. Designs easy to use materials
9. Meets needs of all
10. Includes consumers
Understanding leads to better outcomes

- Patients use health information better and take medicines as instructed
- Providers build stronger relationships with patients and improve trust
- Systems save money and time
# The Cancer Control Continuum

## 5 areas:

<table>
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<tr>
<th>Prevention</th>
<th>Detection</th>
<th>Diagnosis</th>
<th>Treatment</th>
<th>Survivorship</th>
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<td>Tobacco control</td>
<td>Pap test</td>
<td>Informed decision-making</td>
<td>Health services and outcomes research</td>
<td>Coping</td>
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<td>Diet</td>
<td>Mammography</td>
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<td>Health promotion for survivors</td>
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<td>Virus exposure</td>
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<td>Alcohol use</td>
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<td>Chemoprevention</td>
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## Crosscutting Issues

- Communications
- Surveillance
- Social determinants of health disparities
- Genetic testing
- Decision-making
- Discrimination of evidence-based interventions
- Quality of cancer care
- Epidemiology
- Measurement

Adapted from David B. Abrahams, Brown University, School of Medicine
Tobacco control study results

Patients with lower health literacy:
- Have higher nicotine dependence
- Have less knowledge about the health risks of smoking
- Feel less vulnerable to the health risks of smoking

Health literacy opportunities
- Higher health literacy was associated with the key predictors of quitting
- Smoking cessation messages need to be:
  - Written in plain language, with visual aids
  - Culturally competent
- Providers can communicate health risks by using one-on-one teaching and Teach-back, an evidence-based strategy for checking patient understanding

Stewart et al., 2013
Survey results for African American women:

- Less than 65% average knowledge score about HPV, the vaccine, and cervical cancer (65%)
- 61% knew about the HPV vaccine (61%)
- 35% could identify preventive tools, including vaccination and screening (35%)
- Only 35% of women eligible for vaccination had been offered it (35%)

Prevention: Vaccination study results

Strohl et al., 2015
Prevention: Vaccination study results

Health literacy opportunities

- Increased knowledge is needed for prevention
  - Connect vaccination to cervical cancer prevention

- Education programs need to target:
  - People most at risk for cervical cancer death
  - People with decision making power, such as parents

- Programs must be culturally appropriate, in plain language, and delivered in partnership with trusted community organizations

Strohl et al., 2015
Write prevention materials in plain language

Focus
Content
Structure
Behavior
Design
Barriers to detection:

- Low knowledge about free preventive screenings
- Misunderstandings about purpose of screenings
- Low knowledge about recommended screening schedules
- Negative attitudes towards screenings
- Low confidence in ability to get screenings
Barriers to detection due to low health literacy

- Low health literacy impacts individuals’ understanding of the concept of screening and awareness of its benefits
- Patients with inadequate health literacy often don’t understand cancer terms such as:
  - Screening
  - Colon
  - Tumor
  - Lesion
  - Cure

Davis et al., 2002
Detection: Colon cancer screening study results

Participants who used a web-based decision aid tool:
- Were 5 times more likely to prefer colorectal cancer screenings
- Had increased readiness to get the screening
- Had more tests ordered and completed
Detection: Colon cancer screening study results

Health literacy opportunities:

- Web-based programs that use multiple education methods, such as video and animation, can increase awareness of colorectal cancer and screenings.
- Printed handout helps patients remember what they learned and triggers conversation with provider.
- Only 1/3 of patients who wanted immediate screenings had tests ordered, suggesting additional barriers to testing.

Miller, et al., 2011
Interactive decision aid example
Barriers at time of diagnosis:

- Providers use medical jargon when describing disease and treatment
- Emotional responses can hinder patient understanding and retention
- Vulnerable populations use preventive care less often, which can lead to late-stage diagnoses

Davis, 2002
Diagnosis: Barriers in decision-making study results

Misconceptions about cancer treatment:

54% believed or were unsure about the statement: “Surgery can cause cancer to spread throughout the body.”

42% believed or were unsure about the statement: “There is currently a cure for cancer, but the medical industry won’t tell the public because they make too much money treating cancer.”

32% believed or were unsure about the statement: “Pain medications are not effective in reducing the amount of pain people have from cancer.”

Gansler, 2005
Diagnosis: Barriers to understanding risk study results

Patients may have difficulty calculating and applying complicated or unclear risk information.

Providers may have difficulty accurately predicting how long a patient has to live.

Bottorff, 2004; Christakis, 2000
Patients had volunteer lay navigators (VLNs):

- VLN met 4 patient needs:
  - *Emotional*: Supported patients in an empathetic and nurturing role
  - *Information*: Linked patients to the medical system and other services, such as counseling
  - *Family*: Facilitated conversations between family members and participants
  - *Complex*: Connected patients to healthcare providers

- Patients were satisfied with the program’s ability to meet their needs (average score of 4.3 on a 5 point Likert scale)

**Diagnosis: Navigation and lung cancer study results**

Lorhan, et al., 2014
Diagnosis: Navigation and lung cancer study results

Health literacy opportunities:

- Patients need help navigating the cancer care continuum
- Committing resources to navigation can help patients:
  - Coordinate, understand, and access cancer care
  - Reduce anxiety and address concerns
  - Increase self-efficacy

Lorhan, et al., 2014
Understanding of prostate cancer results:

- Understanding went up for 12 of the 19 tested terms
- Significant increase in the number of patients who could correctly locate the prostate and identify the functions of the bladder, bowels, rectum, and prostate

Increase in comprehension of prostate cancer

Wang, et al., 2015
Treatment: Understanding of prostate cancer study results

Health literacy opportunities:

- Plain language and clear visuals increase understanding
- Patients with all literacy levels find videos helpful
- Increasing understanding can enhance patient involvement in the decision making process at any stage of the cancer continuum
Palliative care can begin at the start of a serious illness and be given alongside treatments.
Early discussions about palliative care can lead to:
- Better quality of life
- Lower rates of depression
- Less aggressive care at end of life
- Longer life

Discussions about hospice care in stage IV:
- 53% had a hospice discussion
  - 70% of patients who had the conversation used hospice
  - 26% of patients who didn’t have the conversation used hospice

Palliative care is not just for the end of life

**Palliative care:**
- Provides relief from pain and other symptoms
- Supports quality of life
- Focuses on patients with serious illness and their families

**Types of palliative care:**
- **Basic care** delivered by primary care doctors, disease specialists, such as oncologists, and other professionals
- **Specialty palliative care** delivered by palliative care specialists
- **Hospice care**
### Palliative care and health literacy

<table>
<thead>
<tr>
<th>Health care professionals should:</th>
<th>Health literacy considerations:</th>
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<tbody>
<tr>
<td>● Start conversations about advance care planning and include patients’ wishes in care plans</td>
<td>● Clear spoken and written communication:</td>
</tr>
<tr>
<td></td>
<td>○ Explain jargon words</td>
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<td>○ Help fill out forms</td>
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<tr>
<td>● Have ongoing conversations about advance care planning</td>
<td>○ Focus on patient-centered care</td>
</tr>
<tr>
<td>● Give evidence-based information about care options and informed decision making for treatment and care</td>
<td>○ Cultural considerations about death and dying</td>
</tr>
<tr>
<td>● Counsel patients and family members on emotional distress</td>
<td>○ Shared-decision making</td>
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<tr>
<td></td>
<td>○ Acknowledge and talk about emotions</td>
</tr>
</tbody>
</table>

Institute of Medicine (IOM), 2014
Survivorship wallet card study results:

- 90% found the language used to be “easy” or “very easy” to understand
- ½ of patients planned to share the card with another provider and ¼ already had

Increase in knowledge among cancer survivors

Ulloa, et al., 2015
Survivorship: Wallet card study results

Health literacy opportunities

- Using plain language, the patient’s preferred language, and patient-specific cancer-related information can increase understanding.
- Using handouts to supplement spoken instruction can increase understanding and retention.
- The physical wallet card helps patients communicate medical history to providers.
Areas of cancer survivorship

- Physical symptoms & conditions
- Psychosocial concerns
- Health-related quality of life
- Health behaviors
- Special populations
- Economic impact of cancer
- Research tools & platforms
- Disease progression, recurrence & survival
- Patterns & quality of care

Cancer Survivorship

Office of Cancer Survivorship (OSC), National Cancer Institute
Health behaviors and health literacy

Patients with low health literacy have fewer healthy behaviors:
- Get less physical exercise
- Eat fewer fruits and vegetables
- Are more likely to smoke and drink

Use health-literate communication strategies to educate cancer survivors about the importance and benefits of healthy behaviors
Economic impact and health literacy

Health-literate strategies can help cancer survivors understand their rights when they return to work:

- Avoid stigmas based on misunderstanding of cancer and its treatments, stereotypes, and wrong assumptions about what cancer survivors can do
- Decide what information to share with an employer
- Consider health insurance concerns
Patterns & quality of care and health literacy

Health literacy can improve care for cancer survivors:

- Quality patient-provider communication creates a trusted relationship
- Help survivors follow a care plan
- Help survivors understand the physical and emotional changes and how to cope
What questions or comments do you have for me? Let’s talk.
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