GSA Webinar Series

Health Literacy Considerations for Cancer Prevention Initiatives With Older Adults

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Health Literacy Considerations for Cancer Prevention Initiatives With Older Adults

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Special challenges
Concerns
Noted preferences

THE FOCUS ON OLDER ADULTS

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Older Adults: Literacy & Health

PIAAC shows that while skills decrease with age, the need for managing one's health and well-being increases.

Source: *Numeracy Practices and Numeracy Skills Among Adults*, OECD Working Papers, No. 177. OECD. 2018.

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Special Challenges

Age-related changes:
- Decline in literacy practices
- Limited literacy skills
- Decline in cognitive abilities
- Development of physical impairments [vision & hearing]
- Psychosocial issues [e.g. ageism, isolation, time related stressors]

Concerns:
- Agency
- Memory
- Unrealistic Expectations
- Taboo subjects

Social norms:
- Social stigma/bias
- Difficult conversations
- Difficult decisions

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Abstract concepts
Fear avoidance

A FOCUS ON CANCER PREVENTION

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Preventive Care

Older adults who <u>score</u> higher on the most recent literacy survey (PIAAC) have an increased probability of having done the following in the past year:

- Dentist visit
- Mammogram (Women)
- Pap smear (Women)
- Screen for prostate cancer (Men)

Source: Feinberg 2013 PIAAC analysis

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Literacy Issues Related to
Cancer Prevention

- The assessed *demands* of health-related literature far exceed the documented literacy skills of the public
- *Cancer*, long used as a negative metaphor, remains a fearful topic
- *Prevention* is an abstract concept compared with more concrete terms such as treatment

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Our Challenge

Studies of doctors' communication skills, of the needs

of elderly patients with cancer, and of available cancer information indicate that cancer communication has not met the documented literacy needs of the public or of the older adult population in particular.

Source: Rudd, *Gerontologist, 2019*

Can we do better with cancer prevention efforts?

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New understanding of health literacy
Practice considerations for each component

HEALTH LITERACY INSIGHTS AND GUIDELINES

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Interacting Factors of Health Literacy

Skills of Individuals   **Skills**   Skills of Professionals

Health Literacy

Talk, Writing, and Postings   **Texts**   **Tasks**   Action to Be Taken

Proximal Tasks
Distal Tasks

Emotional and Physical Issues   **Contexts**   Institutional Norms, Structural Facilitators, and Barriers

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Health Literacy Insights for Practice: **Skills** of Older Adults

- 1992 NALS:
  - 71% demonstrated limited prose literacy
  - 68% had difficulty finding and processing quantitative information
  - 80% had difficulty filling out forms, reading, following directions, using schedules
  - Many do not believe that they have a problem

- 2003 NAAL:
  - 3% scored as proficient with health literacy skills
- 2003 HALS:
  - ~80% performed in the two lowest levels of proficiency
  - Retired adults living below the poverty level have the lowest score

- 2011 PIAAC:
  - Literacy, numeracy, and digital problem solving skills decline with age

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Difficulties Faced

15 million U.S. older adults (age 55-74) have low literacy skills (level 1 and below) and are likely to have difficulty to:

- Obtain, process, and understand basic health information
- Navigate the healthcare system
- Share personal information
- Engage in self-care and chronic-disease management
- Understand probability/risk

Source PIAAC 2011
Office of Disease Prevention and Health Promotion

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Improve Skills

- Support and increase adult education opportunities
- Support and increase patient education opportunities
- Integrate patient-centered care with community resources

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Reduce Demands

- Slow the pace of talk
- Provide summaries (e.g. via notetakers, handouts)
- Adhere to plain language guidelines
- Apply teach-back
- Provide health education sessions
- Improve health materials
- Leverage technological advances

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Noted Preferences

- Slower paced talk
- Accessible information
- Clear layout, design, and organization in materials
  - Health messages and educational materials
  - Forms
  - Directions
- Aides such as notetakers and navigators
- Adaptive technology

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Health Literacy Insights for Practice: **Skills** of Health Professionals

Consider communication preparation for health professionals

- Speaking
  - Teach-back

Assessment ?

- Listening and feedback
- Teaching
- Writing
- Choosing appropriate materials

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Enhance Skills

- Raise Awareness:
  - Literacy of US adults
  - Challenges for elders
- Encourage Practice:
  - Visit prep
  - Turn-taking
  - Teach-back
  - Question asking encouragement
  - Reviews
  - Follow-up
- Provide Aides:
  - Note takers
  - Distribution of appropriate materials, reminder cues, follow-up plan
- Improve Opportunities:
  - Professional preparation
  - Licensing exams
  - Continuing education program
  - Grand rounds

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Reduce Demands

Attend to institutional norms, practices, and policies
- Patient load
- Support staff
- Time
- Preparation time
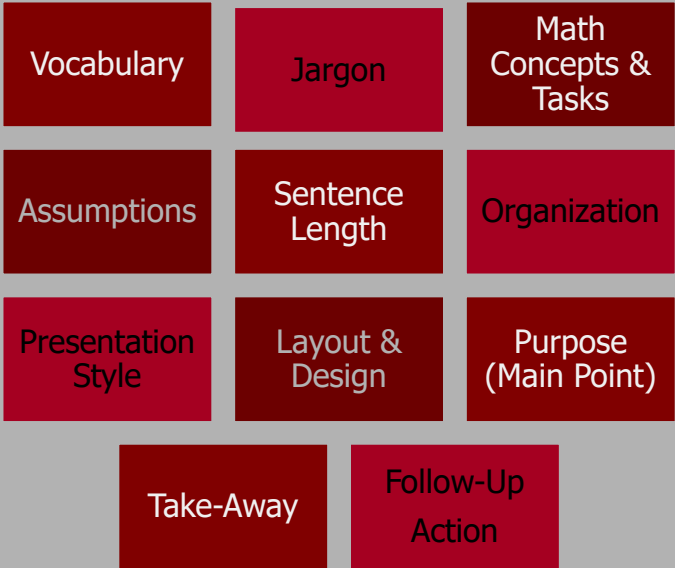- Access to suitable materials

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Health Literacy Insights for Practice:
Texts

- More than 3,000 published studies indicate that health materials are written at levels that <u>far exceed</u> the documented skills of the U.S. public
- <u>Available</u> information is not necessarily <u>accessible</u>
- Multiple guidebooks and assessment tools are freely available <u>but</u> are infrequently used/cited in the development and design of materials

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Vocabulary	Jargon	Math Concepts & Tasks
Assumptions	Sentence Length	Organization
Presentation Style	Layout & Design	Purpose (Main Point)

Take-Away Follow-Up Action

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Clarify Information

- Apply knowledge/lessons learned to ease the burden
- Talk with
- Use plain language/ "translations" into every day words
- Offer explanations
- Do the math

- Follow design guidelines to ease reading and comprehension
- Provide introductions (purpose and main point)
- Organize and highlight
- Summarize key points
- Provide action steps

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Sample Strategies

- Talk and Writing:
  - Encourage the story
  - Reflect insights and experience
  - Attend to emotions
  - Engage in turn taking
  - Assume responsibility for communication
  - Check for clarity
  - Organize messages
  - Attend to vocabulary
  - Highlight key messages
  - Apply plain language guidelines

- Data:
  - Use clear charts and visuals
  - Use tested decision aids
- Medicine:
  - Offer full explanations
  - Provide Rx for learning
  - Conduct brown bag medicine check
- Support an empowering relationship

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Do the Math

Helpful Actions

- Provide numeric information: Numbers matter
- Reduce cognitive effort required
- Provide meaning and context for numeric information
- Draw attention to important information
- Set up appropriate systems to assist and review

Sources: Apter,2007; Peters, 2006; Ancker, 2006; Zikmund-Fisher, 2019

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Consider Difficulties

Ease the Burden: Move Up and Left

Source: Apter 2008

Numeracy Element	Level of Patient Mastery		
	Describe	Interpret	Decision-Making
Reading numbers, counting, telling time			
Arithmetic operation			
Estimation of size, trend			
Frequency			
Percentage			
Problem-solving and inferring the mathematical concepts to be applied			
Logic			
Reading tables			
Reading graphs			
Reading maps			
Estimation of error, uncertainty, variability			
Relative versus absolute			
Risk cumulative, relative, conditional)			

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Provide a Context for Data
Not Just a Number

- Focus on increasing information evaluability
- Provide user-relevant contextual information

    Such as: thresholds, comparison standards, meaningful categories, significant difference
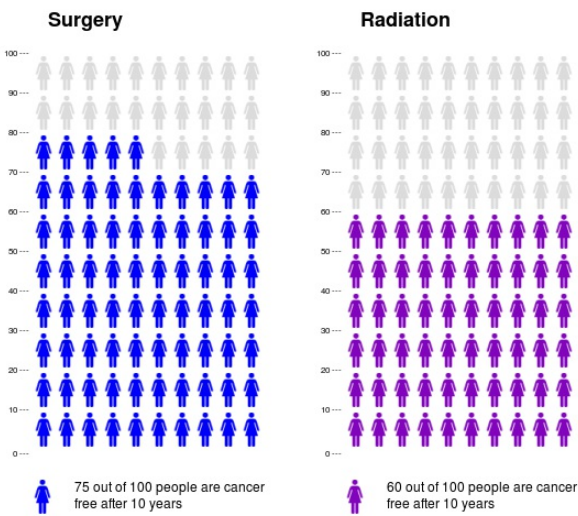
Source: Zikmund-Fisher, 2019

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Helpful
Data Display

- Provide easy comparisons
- Use icon graphics or bar charts

Source: Zikmund-Fisher
iconarray.com

Cancer-Free Survival, By Treatment Option

Surgery — 75 out of 100 people are cancer free after 10 years

Radiation — 60 out of 100 people are cancer free after 10 years

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Apply Scientific Rigor

- Conduct rigorous formative research
- Engage with members of the intended audience
- Follow existing guidelines for the presentation of information
- Pilot test and revise with members of the intended audience
- Assess and revise using existing tools

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Health Literacy Insights for Practice: **Tasks**

Proximal Tasks

Those tasks one must perform while using texts, such as:

- Locate information
- Compare and contrast
- Interpret

Distal Tasks

Those tasks one must perform after using the texts, such as:

- Follow directions
- Calculate [e.g. dosage, time]
- Use tools
- Monitor and measure
- Document

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Deconstruct Tasks

Deconstruct health activities
to understand the complexity
of health tasks, health texts, and health-related tools

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Simplify Proximal Tasks

Example: Forms
- No overlay with design
- Plain language principles followed
- Adequate entry space – large enough for handwritten entry
- Logical groupings
- No dependent questions (if yes/if no)
- Clear answer options
- Explanations for new structures
- Option for NA

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Simplify Distal Tasks

Examples:
- Pilot test instructions and revise as needed
- Develop and review plans
- Set up demonstrations for new tools
- Provide illustrations
- Develop reminder cues

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Health Literacy Insights for Practice:
Contexts

Consider the environment within which activities take place

Examine the capacity of professionals and health institutions to provide accessible information and to support the active engagement of people seeking care and services

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A Complex Environment

- A work setting and a care setting
- A foreign land
- Design Elements
- Atmosphere
- Expectations
- Demands
- Appropriate behaviors

- Culture of its own
  - Language
  - Dress
  - Protocols
  - Behaviors
  - Expectations
  - Sanctions

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Change

- Identify and minimize emotional and physical distractors
- Consider appropriate learning times and processes
- Identify and minimize constraints (such as time issues)
- Examine policies, protocols, and regulations that could support facilitating factors (agency, dignity, clarity)

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Assess Environmental Factors

Walk-About

Navigation: one issue in the interaction of person and place

Signage: metaphor for complexity

- First impressions
- Walking interview
- Analysis

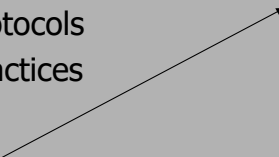Source: Rudd et al 2019

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HLE2

Assessment tool:

- Organizational policies
- Institutional practices
- Navigation
- Culture and Language
- Communications

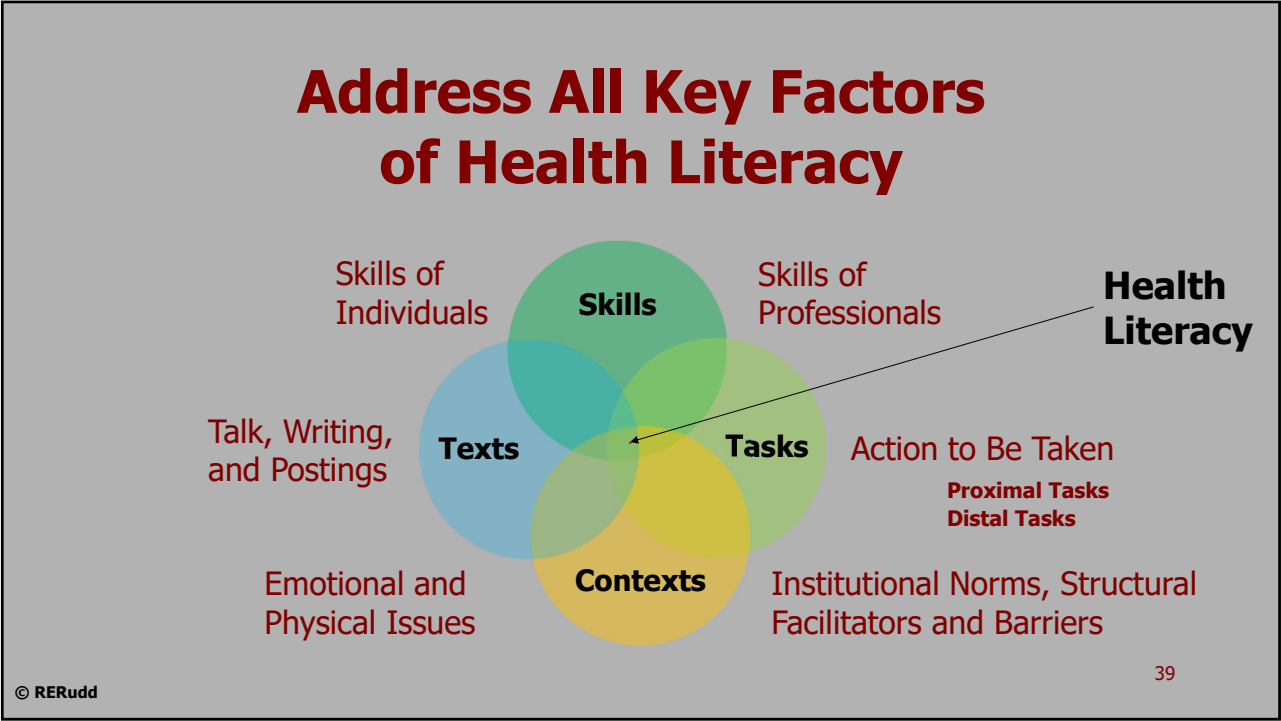## Health Literacy Environment Considerations

- Policies and Protocols
- Institutional Practices
- Navigation
- Communication
  - – Written materials
  - – Forms
  - – Websites
  - – Patient Portals
- Culture and Language

- Institutional Contracts
  - - Forms
  - - Test results
  - - Response letters
  - - Instructions
  - - Directions
  - - Patient education
  - - Doctor's notes
  - -Measures and trends

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Address All Key Factors of Health Literacy

Skills of Individuals

Skills

Skills of Professionals

Health Literacy

Talk, Writing, and Postings

Texts

Tasks

Action to Be Taken

Proximal Tasks
Distal Tasks

Emotional and Physical Issues

Contexts

Institutional Norms, Structural Facilitators and Barriers

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The Appeal of Health Literacy Work

From the Philosophic or Political Perspective:
- Links to social justice
- Links to health disparities
- Links to international consensus: Literacy as a Right
  (Universal Declaration of Human Rights, 1948)

From the Practical Perspective:
- Literacy can be improved
- Communication skills can be improved
- Texts are malleable and can be made easier to access
- Processes can be examined and modified
- Environments can be examined and changed
- Action is plausible and possible

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Time for Action

Documented: Significant proportions of adults in most industrialized nations have limited literacy and numeracy skills

Documented: Literacy skills are linked to social factors

Documented: Literacy skills are linked to health outcomes

Documented: Mismatch between reading level of health materials and average reading skills of adults

Documented: Health systems and health care processes have become increasingly complex

Implications: Health Disparities

Action: Remove Barriers

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Apply Rigor

Practice
- Attention to adult literacy assessments
- Respectful attention to health communication

Insistence on scientific rigor
- Formative research
- Testing with members of the intended audiences

Policy Changes
- Plain language initiatives
- Professional education and training
- Regulations for development and dissemination of health information
  - Professional norms & practices
  - Institutional Review Boards and rigorous standards
  - Contractual obligations

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Resources
Sample of Freely Available Measures

CDC: Health Literacy Index, Measure of written health information

AHRQ: PEMAT, Measure of written and AV health information

Canada: Canadian Public Health Association: Working with low literacy seniors

HSPH: Health Literacy Site
- HLE2: Assessment tool for the Health Literacy Environment of Hospitals and Health Centers
- SAM
- PMOSE/IKIRSCH

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Questions?

- We will not be using the "raise hand" feature today
- Please use the "questions" feature accessible on the right side of your screen
- If we do not get to all of the questions today, we will email responses after the webinar

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Opportunities for Cancer Prevention During Older Adulthood

- ✓ Free to view
- ✓ Sponsored by CDC's Division of Cancer Prevention and Control

CANCER IS **NOT** AN INEVITABLE ASPECT OF GROWING OLD

WE CAN DO MORE TO **REDUCE CANCER RISK** AND PRESERVE HEALTH AS PEOPLE AGE

https://academic.oup.com/gerontologist/issue/59/Supplement_1

Webinar Evaluation

In an effort for continual improvement, we would like to hear your thoughts. Please provide feedback by clicking the survey link at the end of the webinar.

Thank you again and we hope you enjoyed the program!

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Thank You

Visit GSA's webinar page to register for upcoming webinars on cancer prevention or view archived recordings:

- Health Literacy Considerations for Cancer Prevention Initiatives With Older Adults (Friday, June 28, 2019)
- Sun Protection and Sunburn Among Older U.S. Adults (Friday, August 2, 2019)

www.geron.org/cancerprevention

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Thank You

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