Improving Access to Communication for Adults with Aphasia using Aphasia-Friendly Tools

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Overview

- The problem with patient-provider communication
- Communication vulnerable adults
- Aphasia
- Aphasia Friendly
- Improving patient-provider communication
The Problem with Patient-Provider Communication

- Communication access is mandated by law
- Do providers know how to communicate with people with communication disorders?
- Just because there is a need for training, it does not mean it will be implemented
- Communication breakdown could result

Blackstone et al., 2015; Bums et al., 2012
Communication vulnerability

Definition
The diminished capacity of an individual to speak, hear, understand, read, remember or write due to factors that are inherent to the individual or related to the context or situation (Blackstone et al., 2015, p. 13).

- At risk for impaired access to effective language / communication
- Impaired access when required to use standard health-care related forms and documents

Blackstone et al., 2015
Communication vulnerable adults

- Vision impairment
- Hearing impairment
- Cognitive impairment
- Non-native English speakers and people with other cultural differences
- Adults with low health-literacy skills
People with Vision Impairments

As many as 21 million Americans may have a "vision problem"

- Lack of accessibility to health and health-related documents
- Inconsistent use of accommodations such as Braille, large print, and magnifying devices
- Lack of universal design principles for written materials, i.e. white space etc.

Why is vision a public health problem, 2015; Chung, 2013; Warren, 2013
People with Hearing Impairments

37 million adults in the United States have trouble hearing

- May have a wide range of hearing problems from deafness to mild impairments
- May have lower literacy skills when compared to hearing individuals
- May go unnoticed or misunderstood, i.e. misconception that they can lip read and write efficiently
- Lack of access to typical instructions given to hearing adults, i.e. Emergency Preparedness Materials
  - Digital video-based instructions in sign language

Schoenbom & Heyman, 2010; Smith & Samar, 2016; Neuhauser et al., 2013
People with Cognitive Impairment

Approximately 16 million people with a cognitive impairment in the U.S.

- Mild Cognitive Impairment (MCI)- zone between typical age-related cognitive decline and the disease dementia. Difficulties in memory, language, thinking, and judgement.
- People with MCI have lower performance on literacy
- Intellectual Disability (ID)- significant limitations in intellectual and adaptive behavior which includes every day pragmatic skills.
- Health providers do not think people with ID are able to be used in research
- Simple language, pictures, and symbols

Center for Disease Prevention and Control, 2011; Mayo Clinic Staff, 2016; Han et al., 2015, American Association on intellectual and developmental disabilities n.d.; Chinn, 2014.
Non-native English Speakers

More than a million people in the U.S. speak one of six languages other than English.

- Translated written materials need to be
  - Easy to read
  - linguistically appropriate
  - culturally appropriate
- Transcreation allows for cultural concepts and language to be appropriate for all audiences
- Solomon et al., 2005

Blackstone et al., 2015; Andrulis & Brach 2007; Solomon et al., 2005
People with Low Health Literacy Skills

Only 12% of adults possess proficient health literacy skills

- May not understand health condition or ways to improve health
- Negative health implications
  - Decreased medication adherence
  - Decreased self-management skills
  - Decreased knowledge of disease
- Increasing health related knowledge
  - Ask Me 3
  - Teach-Back Method

Blackstone et al., 2015; Sorenson et al., 2012; Six-Means et al., 2012; MacLeod et al., 2014
Aphasia

Definition:
An acquired language disorder of neurologic origin that impairs a person's expression and reception of language.

- Most common cause: cerebrovascular attack (stroke)
- Occurs in approximately 33% of stroke survivors
- Any injury or disease that affects the part of the brain that supports language

Hallowell, 2017; Pederson et al., 1995; National Aphasia Institute, n.d.
Describing the Effects of Aphasia

- Difficulties producing language, understanding language, reading and writing
- Difficulties finding, retrieving, and speaking words that convey meaning
- Difficulties comprehending written material
- Difficulties with accessing health-related documents
- Impacts the quality of life

ASHA, n.d.; Hallowell, 2017
Aphasia-Friendly

- A style of presentation
- Current health forms provided to PWA are not written at an appropriate reading level
- PWA comprehend more information in an aphasia-friendly format
- Personal preference are crucial to the formatting

Rose et al., 2003; Brennan et al., 2005
Aphasia-Friendly Content Characteristics

- Simplified Vocabulary
  - High frequency words
  - Personally relevant words
  - Easily depicted in pictures

- Simplified grammar/syntax
  - Subject/verb/object sentence
  - Few words in a sentence

Rose et al., 2011; Brennan et al., 2005; DeDe, 2012; Rose et al., 2003
Aphasia-Friendly Content Characteristics cont.

- Graphics and Illustrations
  - Do not use Clipart or line drawings
  - May feel disrespected
- May not always facilitate comprehension
- Authentic depictions and colors

Rose et al., 2011; Brennan et al., 2005; DeDe, 2012; Rose et al., 2003
Aphasia-Friendly Form Characteristics

- **Font**
  - 14 pt. font or larger
  - Simple font style, i.e. sans serif
  - Lower case letters in most text

- **White space**
  - 1.5 line spacing
  - Larger margins

Brennan et al., 2005; Hallowell, 2017; Rose et al., 2014
Aphasia-Friendly Documents
Emotional Changes After Stroke

Stroke can cause changes to your mood. These changes may include:

**Post-Stroke Depression (PSD)**

PSD is common after stroke.

- You may feel sad
- You may feel tired
- You may have difficulty concentrating
- You may eat too much or not enough
- You may lose interest

**What you can do:**

Call your doctor if you think you have PSD.
Prevent Stroke

- See your doctor regularly
- Learn about your risk factors
- Learn how to change your risk factors

Risk factors

Risk factors increase your chance of having another stroke.
Make changes to reduce your risk factors.
Small life changes can help you prevent stroke.
What is Aphasia?
Aphasia is a language disorder that affects the ability to communicate. It's most often caused by injury to parts of the brain that control speech and language resulting from a stroke.

I need to communicate with someone who has aphasia.

- **Keep It Simple**
  - Speak in short, simple sentences.

- **Be Patient**
  - Allow plenty of time for a response. Talk with him/her in short, simple sentences.

- **Remove Distractions**
  - Turn off radios and TVs.

- **Be Creative**
  - Try writing, gesturing, pictures and communication tools like an iPad.

- **Confirm**
  - Repeat back what you think he/she is saying.

People With Aphasia
1. Communicate differently, but they are as smart as they were before.
2. Their hearing is fine, speaking loudly does not help.
3. Aphasia is not contagious! It is not contagious! If you talk to people with aphasia, you just have to communicate differently.

I have aphasia.

- **Take Your Time**
  - Remember it may take a while to get the words out.

- **Let People Know What Works Best For You**
  - Do you want a question asked in multiple ways? Let them know.

- **Use Assistive Devices**
  - Bring photos, diagrams, pen and paper, etc.

- **Getting Frustrated Is Okay**
  - Don't blame yourself if you get stuck or stumble on your words. Be patient with yourself as you find what works.

If You Get Stuck, You Can
1. Admit you're struggling.
2. Recap what you have discussed so far.
3. Decide whether to carry on or come back to it later.

Learn more at StrokeAssociation.org/aphasia and Aphasia.org

©2014 American Heart Association

*Together to End Stroke* | National Aphasia Association

**APHASIA**

A language disorder affecting the ability to communicate. It's most often caused by injury to parts of the brain that control speech and language resulting from a stroke.

**It is NOT a problem with intelligence**

Phone: 1800 274 274
Website: www.aphasia.org.au
Email: questions@aphasia.org.au

*Thank you for your patience.*
National Aphasia Association webpage for people with aphasia to find resources
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*University of North Carolina, Center for Aphasia and Related Disorders*

*Coffee menu: Created by Heather Shelton*
- Include materials to communicate about mood states and activity adaptation

The LIV Cards consist of a boxed set complete with:

- Instruction manual
- Reproducible scoring sheets
A Visual Guide to Visiting Yosemite Valley

APHASIA FRIENDLY
Accessibility

Yosemite National Park is a wonderful and beautiful place with towering trees, thundering waterfalls and massive granite formations. Set aside as a national park in 1890, Yosemite is a place visited by almost four million visitors each year. Yosemite's goal is to provide the highest level of accessibility to our visitors as possible. Each year has shown marked improvements in both physical and programmatic accessibility at Yosemite.

The staff at Yosemite is working hard to correct and resolve accessibility deficiencies throughout the park. By using principles of universal design, Yosemite is committed to providing physical access to the greatest number of individuals. From designing and building new facilities to the rehabilitation of older buildings, accessibility has become a key component of all projects. The park also offers a free fully accessible shuttle bus service in Yosemite Valley to all park visitors.

For more information, download the park's accessibility guide [2 MB PDF], which describes access to areas, facilities, and services for people with disabilities. In addition, our Deaf Services Program is dedicated to connecting the Deaf community to everything Yosemite has to offer. Finally, we have a visual guide to visiting Yosemite Valley for people with aphasia [1.5 MB PDF].
Mission
Give hope to people with aphasia and their families by developing and sharing innovative solutions that reduce language barriers to full life participation.

Vision
There are no barriers to living successfully with aphasia.

From the Aphasia Institute, Toronto
People in Your Life

Are you happy with the number of relationships and friends?

Not happy

Very happy

© 2006 The Aphasia Institute
RESIDENTS' BILL OF RIGHTS

- To be treated with DIGNITY and RESPECT
- Participate in MAKING DECISIONS about your CARE
  - YES
  - NO
  - Medication
  - Case Conference
- Know WHO will HELP you
- INFORMATION
  - Rules
  - Speak Out
- NO ABUSE
  - Physical
  - Mental Abuse
- PRIVACY

Because this is YOUR HOME

From the Aphasia Institute, Toronto
More decisions your medical decision maker can make:

**Life support treatments** - medical care to try to help you live longer

- **CPR or cardiopulmonary resuscitation**
  
  cardio = heart  
  pulmonary = lungs  
  resuscitation = to bring back

  This may involve:
  - pressing hard on your chest to keep your blood pumping
  - electrical shocks to jump start your heart
  - medicines in your veins

- **Breathing machine or ventilator**
  
  The machine pumps air into your lungs and breathes for you.
  You are not able to talk when you are on the machine.

- **Dialysis**
  
  A machine that cleans your blood if your kidneys stop working.

- **Feeding Tube**
  
  A tube used to feed you if you cannot swallow. The tube is placed down your throat into your stomach. It can also be placed by surgery.

- **Blood transfusions**
  
  To put blood in your veins.

- **Surgery**

- **Medicines**

From Easy to read advanced directives, State of California (10 languages)
PWA Response to using Aphasia-Friendly Products

- Current health practices aren’t meeting the needs of PWA
- PWA aren't being asked about formatting
- Activities and participation are very important to PWA
- Aphasia-friendly documents could allow PWA to participate in society

Rose et al., 2014; Worrall et al., 2011; Simmons-Mackie et al., 2016; Aphasia United, 2016
Aphasia-Friendly Advocacy Groups

  - Examples of aphasia-friendly documents
  - Supports people with aphasia, SLPs, and caregivers
  - Educate individuals on aphasia and supply resources

- American Speech Language Hearing Association (ASHA)
  - Promotes assessable information
  - Provides tips to make materials health literate

Aphasia Access, 2016.; ASHA Health Literacy, n.d.
Implications for Practice and Policy

United States
- Simmons-Mackie et al., Published the top ten best practices for PWA

Simmons-Mackie et al., 2016
Implications for Practice and Policy

Examples from other Nations

- Australia: Centre for Clinical Research Excellence- Best Practice Statements forming the Australian Aphasia Rehabilitation Pathway
  - “People with aphasia should have support material available to enable them to participate in communication”
  - “Communicatively accessible environments should be provided for people with aphasia”

- Canada: Aphasia Institute creates and disseminates aphasia-friendly health communication products for PWA & educates providers

- Global level: Aphasia United

Aphasia Pathway, 2014; Chapey et al., 2000; Aphasia Institute, 2015; Wallace, n.d.
Improving Patient Provider Care

- The more successful patient-provider communication is, the more successful the health outcomes are.
- Employees should be trained on effective communication techniques.
- Aphasia-friendly materials should be written, available, and used.
- Adults who are communication vulnerable need to be identified.
- Communication supports need to be put in place i.e. communication boards.

Patak et al., 2009; Rao, 2011; Blackstone et al., 2015
Blackstone, Beukelman, and Yorkston (2015) identified five steps to implement change:

- Leadership
- Identify which patients are communication vulnerable
- Accessibility of Communication Supports
- Teamwork
- Research

Blackstone et al., 2015
Changing Practice and Policy cont.

- The Joint Commission on Hospital Accreditation
  
- Expectations for effective and consistent communication between health-care providers and patients (The Joint Commission, 2017).
  
- A Roadmap for Hospitals- "Advancing effective Communication, Cultural Competence, and Patient- and Family-Centered Care"

The Joint Commission, 2010
Conclusion

- Accessibility should be available to everyone
- The use of aphasia-friendly design principles:
  - Can be used to benefit people with aphasia
  - Can be used to benefit communication vulnerable adults
References


DeDe, G. (2012). Effects of word frequency and modality on sentence comprehension impairments in people with aphasia. American Journal of Speech-Language Pathology (Online), 21(2), S103-S114A.


