Serving Deaf & Hard of Hearing Individuals in Health Care Settings

Cara A. Miller, Ph.D.
Connecticut Case Management Society of America
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Outline

- Introduction
- Definitions
- Terminology
- Models of Deafness
- Language Diversity & Communication
- Experiences of Deaf Individuals in the Healthcare System
- Accommodations & Technology
- Best Practices for Provider Competency
- Resources
Objectives

- Distinguish between models of deafness
- Improve understanding of communication technologies
- Use improved understanding of deafness to tailor interactions with patients
- Improve understanding of how to work with ASL interpreters
- Define the interpreter’s role in the healthcare setting
- Identify & distinguish between helpful modifications for effective communication
Hearing Loss Prevalence

- About 2 - 3 out of every 1,000 children are born with a detectable level of hearing loss either unilaterally or bilaterally
  - More than 90% of deaf children are born to hearing parents.
- 36 million adults report some hearing loss
  - As few as 1 in 8 people (13% - 17% of adults)
- About 2% of adults aged 45 - 54.
- 8.5% of adults aged 55 - 64.
- 25% of adults aged 65 – 74.
- 50% of adults aged 75+
- 2.1 million individuals are identified/diagnosed with hearing loss annually

(NIDCD, 2012)
Causes of Prelingual Hearing Loss

- Prelingual Deaf Children: 1/500
  - Idiopathic: 25%
  - Non-genetic: 25%
  - Genetic: 50%
    - Nonsyndromic: 70%
    - Syndromic: 30%
      - Autosomal recessive: 75% - 85%
      - Autosomal dominant: 15% - 24%
      - X-linked: 1% - 2%

(Gene Review, 2015)
Etiology of Hearing Loss

- Acquired
  - Infection
  - Drug-Related
  - Acoustic trauma
  - Acoustic exposure
  - Structural
  - Unknown

- Genetic
  - Non-syndromic
  - Syndromic
    - Recessive
    - Dominant
    - X-Linked

(NIDCD, 2012)
Defining Hearing Loss By Degrees

- 0 - 15 dB  Normal
- 15 - 25    Minimal Hearing Loss
- 26 - 40    Mild Hearing Loss
- 41 - 55    Moderate Hearing Loss
- 56 - 70    Moderately Severe Loss
- 71 - 90    Severe Hearing Loss
- > 90 dB    Profound Hearing Loss

(NIDCD, 2014)
Factors Impacting Communication

- Age of onset
- Etiology
- Type
- Language skills
- Residual hearing
- Speechreading skills
- Speech abilities
- Cognitive abilities
- Personality characteristics
- Family environment
- Educational background
- Personal preference

(ADK, 2008)
Aspects of the Deaf Experience
Models of Deafness: Medical

- “deaf” or “hard of hearing”
  - Note lowercase “d”
  - Do not see themselves as members of Deaf culture
  - Some may know sign language
  - Primary language is spoken/written English

- “Deafened” (i.e. “late-deafened”)
  - Frequently used by postlingually-deaf adults ages 20+

- “Hearing Impaired”
  - Often used by media, healthcare professionals, & society in general to refer to people with a hearing loss.

- A more acceptable generic phrase is "deaf and hard of hearing" to refer to all people with a hearing loss.
Models of Deafness: Sociocultural

- Deaf People:
  - Members of the Deaf community who share common values, norms, traditions, language, and behaviors.
  - Do not perceive themselves as having lost something (i.e., hearing) and do not think of themselves as handicapped, impaired, or disabled.
  - Celebrate and cherish their culture because it gives them the unique privilege of sharing a common history and language.
  - Are considered a linguistic minority within the American culture. They have their own culture and at the same time live and work within the dominant American culture.
  - Within the Deaf culture, the term "hearing impaired" often is seen as offensive. It suggests that Deaf people are "broken" or "inferior" because they do not hear.
## Models of Deafness, cont.

<table>
<thead>
<tr>
<th>Sociocultural</th>
<th>Medical</th>
</tr>
</thead>
<tbody>
<tr>
<td>Culturally-oriented</td>
<td>Medically-oriented</td>
</tr>
<tr>
<td>Group of people who share a common means of visual communication that provides the basis for group cohesion and identity</td>
<td>Group of people whose hearing loss interferes with the normal reception of speech/hearing</td>
</tr>
<tr>
<td>Linguistic</td>
<td>Condition</td>
</tr>
<tr>
<td>Normality</td>
<td>Abnormality</td>
</tr>
<tr>
<td>Collectivism</td>
<td>Individualism</td>
</tr>
<tr>
<td>Beliefs &amp; Values</td>
<td>Diagnoses</td>
</tr>
<tr>
<td></td>
<td>HOH/Profound/Severe</td>
</tr>
<tr>
<td></td>
<td>Disability</td>
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Health Literacy

- Fill out complex forms
- Locate providers & services
- Understand consent forms
- Share health history with doctor
- Follow doctor’s instructions
- Read the prescription instructions
- Maintain a healthy lifestyle
- Manage chronic diseases*

* Medline Plus (2010)
Health Literacy, cont.

- Deaf adults were found to have lower health literacy compared to their hearing counterparts **
- Global Fund of Information Deficit (Pollard)
- Environmental factors
  - Incidental learning (cannot overhear radio/TV/spoken conversations)
  - Hearing families & lack of communication
  - “Dinner table syndrome” i.e. Mom telling Dad about Aunt Pam’s stroke
- Professional factors
  - Language (e.g. interpretation of “HIV+ test results”)
- Patient factors
  - Insufficient communication (e.g. incorrect use of medication)
  - Illegal practices (e.g. signing consent forms without understanding)

** The Current State of Health Care for People with Disabilities by National Council on Disability, Washington, DC
Barriers & Challenges

- Linguistic and communication barriers
- Inadequate or insufficient technology
- Inadequate communication access in ASL
- Failure of medical training programs to adequately prepare medical staff to communicate with DHOH individuals
- Lack of provider awareness about heterogeneity of DHOH individuals
- Deaf patient mistrust/misunderstanding of healthcare providers
- Differing cultural norms
Deaf Patients’ Experiences

Difficulties with telephone communication:

- “We just go right to the hospital. I wouldn't call my doctor at all. I just go right to the emergency room.”

Lack of information, fear, feelings of mistrust:

- “I was still awake and the doctor kept … pushing me down to make me lay down. I just said ‘I want to know what you're doing,’ and he would say, ‘Don't worry. You're fine. Lay down.’”

Providers’ reluctance to provide interpreters:

- “Some doctors refuse to pay … I request an interpreter and they refuse. They say writing is good enough, writing will do, but sometimes I get stuck and I'm uncomfortable with writing.”
Outcomes of Effective Communication

- Shorter lengths of stay
- Fewer hospital readmissions
- Fewer emergency room visits
- Better treatment adherence
- Better medical follow-up
- Fewer unnecessary diagnostic tests
- Better healthcare outcomes
- Better patient health care satisfaction
Guidelines for Healthcare Providers

- Clearly identify individuals at-risk for poor communication
- Visual Medical Aids
- Providers who know basic sign language
- Establish an effective office communication policy
- Provide qualified sign language interpreters
- Know ineffective methods of communication
- Know effective communication approaches
- Know relevant laws

(National Association of the Deaf)
Clearly Identify Those At Risk

- Clearly identify at-risk individuals for poor communication
- Flag records to indicate at-risk patients
- Enable pop-up windows in patient charts through EMR
- Label patient chart with universally-recognized icon to indicate deafness or communication needs
Use Visual Medical Aids

- To facilitate patient education & communication
- To help explain certain concepts & basic anatomy

- Charts
- Diagrams
- Models
- Online resources to reinforce teaching and understanding
Providers Who Know Basic ASL

- Can enhance patient comfort; however:
  - Usually does not meet level of fluency required for effective communication
  - ASL fluency should be assessed by an accredited certifying body (e.g. RID)
  - Language fluency requires years of training
  - Necessity of honest self-assessment of ASL fluency
  - Importance of receptivity to feedback
  - Use of basic ASL skills as a last resort (i.e. emergency; until interpreter arrives).
Online ASL Medical Resources

- Advocate Illinois Masonic Deaf and Hard of Hearing Program
  - http://www.advocatehealth.com/immc/deafandhardofhearingprogram
- Health Education in American Sign Language
  - http://www.deafhealth.org/
- Health Education for the DHOH Community/Interpreters/Professionals
  - http://www.deafdoc.org
- Deaf Wellness Center
  - https://www.youtube.com/user/DeafWellnessCenter/videos
Office Policies

- Front line staff should ask deaf patients about communication needs.
- Document patient preferences in EMR to facilitate future requests.
- Provide clear documentation on how language or communication needs were addressed with patients at each visit.
- If patients declined communication accommodations, document reasons why.
- Maintain a database of qualified interpreters with expertise in medical settings.
Oral Deaf Patients

- Get attention before speaking
- Highlight key themes
- Define important words
- Speak slowly and clearly
- Keep area around mouth clear
- Maintain eye contact with Deaf person
- Use words “I and you” when speaking to Deaf person
- Avoid standing directly in front of light sources
- If asked to repeat, first repeat verbatim, then rephrase
- Do not assume all individuals can or wish to use pen/paper
- Look directly at Deaf person (facilitates patient-provider alliance)
Types of Interpreters

- Sign language/ ASL Interpreter
- Oral interpreter
- Multi-lingual interpreter
- Tactile interpreter & Support Service Provider (SSP)
- Certified Deaf Interpreter (CDI)
- Video Relay Services (VRS)
- Video Remote Interpreting (VRI)
- CART: Communication Access Real-time Translation
Assessing Need for Interpreters

- Ask about deaf person’s needs or preferences
- Clarify in what setting the interpreting will take place
- Inform interpreter of field-specific jargon
- If written (non-PHI) materials are available, offer copies to interpreter
Working with ASL Interpreters

- Highly skilled professionals who facilitate communication between hearing individuals and Deaf or hard of hearing individuals.
  - Must understand the cultures in which they work and apply that knowledge to promote effective cross-cultural communications.
- Proficient in English & American Sign Language
- Commitment to achieve certification; grow & maintain skills
- Require physical & mental stamina & endurance
- Able to emotionally handle charged & unexpected situations
- Required to adhere to confidentiality
- Must be able to convey feelings & emotions of speakers
ASL Interpreters, cont.

- Always use interpreter for informed consent
- When the interpreter is present, talk directly to the patient
- Avoid talking about the patient in their presence
- Avoid saying, “ask him” or “tell her”
- Maintain eye contact with Deaf patient
- Ask Deaf person to choose best seating for communication
- Interpreter will stand or be seated near primary speaker
- Allow time to view visual aids before offering explanations
- Slow down pace of communication slightly
If appt is 60+ minutes, team of 2 interpreters may be needed; will alternate

Schedule breaks during meeting

Do not address interpreter directly unless needed

Interpreters may leave room along with medical provider

Interpreters may wait outside patient room in absence of healthcare provider
ASL Interpreters, cont.

- Code of Ethics
  - Accuracy, confidentiality, impartiality

- Use certified interpreters with additional skill or training in medical interpreting
  - Fewer clinical errors
  - Higher patient satisfaction
  - Better clinical outcomes
  - Familiar with medical terminology and context
  - No medical certification exists; however, medical interpreting requires training and experience

- When hiring interpreters, inquire about medical interpreting experience, medical interpreting CEUs, relevant education in interpreter training programs, collaborations with skilled medical interpreters.
Interpreter Referral Sources

- State Commission on the Deaf and Hard of Hearing
- State Association of the Deaf
- National Association of the Deaf (NAD)
- Registry of Interpreters for the Deaf (RID)

- Avoid using family members!!!!!
  - Seldom objective
  - May be emotionally distraught
  - May be unable to deliver difficult news
  - Confidentiality is an issue
  - Their use is not legally defensible in a court of law for all but the most extreme emergencies and even then, only until a qualified interpreter can be sought.
Tactile Interpreting & CDIs

- Patients who are DeafBlind or have low vision
  - May require a tactile sign language interpreter
  - May be accompanied by a support service provider (SSP)
- Use of Certified Deaf Interpreters (CDIs)
  - Certified interpreters who work in tandem with a hearing ASL interpreter
  - Specially trained to facilitate communication between medical provider &
    - Deaf individuals with poor communication skills secondary to language deprivation
    - Deaf individuals who use a foreign language
    - Deaf individuals who use home-based sign language unfamiliar to hearing ASL interpreter
VRI: When Is It Appropriate?

- Emergency Room: admissions information for triage to formulate treatment plan
- Pre-OP, to explain procedure, fill out hospital questionnaire, consent form, etc.
- Prior to a routine procedure, i.e. x-ray, MRI, CAT scan, physical therapy, etc.
- Short routine office visit (< 30 mins)
- Doctor’s rounds
- When medical staff needs to talk to a patient who is hospitalized for an update on patient’s status
- Discharge planning
VRI: When Is It Not Appropriate?

- Post-operation
- Equipment barriers (lead-shielded rooms, etc.)
- Patient is not coherent
- Patient inability to use VRI or personal preference to have on site interpreter
- Emotionally sensitive information
- Complicated and risky procedures
- Certain mental health situations i.e. patient is in restraints etc.
To VRI Or Not To VRI?

The hospital personnel should always explain interpreting service options fully to the deaf patient when making a medical appointment. The final decision of how the communication is to be handled should always be left to the deaf person. VRI should never be forced on a deaf patient.
CART

- Computer Aided Real-time Translation
- Instant translation of the spoken word into English text performed by a CART reporter using a stenotype machine, laptop, and realtime software.
- Text is then displayed on a computer monitor or other display device for the person who is deaf or hard of hearing to read.
- Primarily used by people with hearing loss, but has also been used by people with learning disabilities or those who are learning English as a second language.
Assess Patient Understanding

- Use Teach-Back to Assess and Ensure Patient Understanding
- More information on Teach-Back Method here:

- Many deaf people, particularly in medical settings, will feign to understand and nod their heads in agreement.
- This is usually not an indication that they are understanding but as a result of feeling reticent to inform the health care professional that they are NOT able to understand.

- Examples of Teach-Back:
  - “I want to be sure that I explained your medication correctly. Can you tell me how you are going to take this medicine?”
  - “We covered a lot today about your diabetes, and I want to make sure that I explained things clearly. So let’s review what we discussed. What are three strategies that will help you control your diabetes?”
  - “What are you going to do when you get home?”
Laws Related to Access

- **Section 504 of the Rehabilitation Act of 1973**
  - Mandates equal access for all federal health care services and facilities and health care providers who are also recipients of federal financial assistance.

- **Title II of the Americans with Disabilities Act**
  - Mandates equal access on all public (state and local) health care providers.

- **Title III of the Americans with Disabilities Act**
  - Mandates equal access on all private health care providers.

- **Title VI of the Civil Rights Act of 1964**
  - Mandates appropriate language access in the health care setting to individuals who have limited English proficiency.

- State laws often mirror the above federal laws and provide separate remedies.
Hearing Assistance Dogs

- Fire and smoke alarms
- Sirens
- Telephone rings and buzzes
- Oven timers
- Alarm clocks
- Doorbells and door knocks
- Person’s name being called
- Baby’s cries
- Dryer and washer signals
- Microwave beeps
- Fax machines
- Dropped keys, items
- Teakettle whistles
- And more…
Etiquette Around Assistance Dogs

- Do allow the dog to serve as a working partner without distraction
- Do speak to the person, not the dog
- Do understand that releasing the dog to interact might be distracting
- Do ask if the dog is an assistance dog
- Inform the person if the dog is doing something inappropriate
- Do expect the most appropriate behavior from the dog

- Don’t make the dog the center of attention
- Don't attempt to pet or touch an assistance dog without asking the partner
- Don't distract the dog from its work or attempt to feed
- Don't automatically tell the person that there are no dogs allowed
- Don't assume that the dog is not an assistance dog because the person doesn't look disabled
Information Sources


- Advocate Illinois Masonic Medical Center: Deaf and Hard of Hearing Program: http://www.advocatehealth.com/immc/deafandhardofhearingprogram


Information Sources, cont.


Working with Deaf People: A Handbook for Healthcare Professionals

Anna Middleton, Ed.

2009

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