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Author(s): Philip Zazove, M.D., F.T.W.D. Professor of Family Medicine, 2010

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When the Phone Rings, My Bed Shakes:

Hearing Loss from a Family Doc's Viewpoint

Philip Zazove, M.D., F.T.W.D.
Professor of Family Medicine
University of Michigan
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University of Michigan
Medical School

Disclaimer

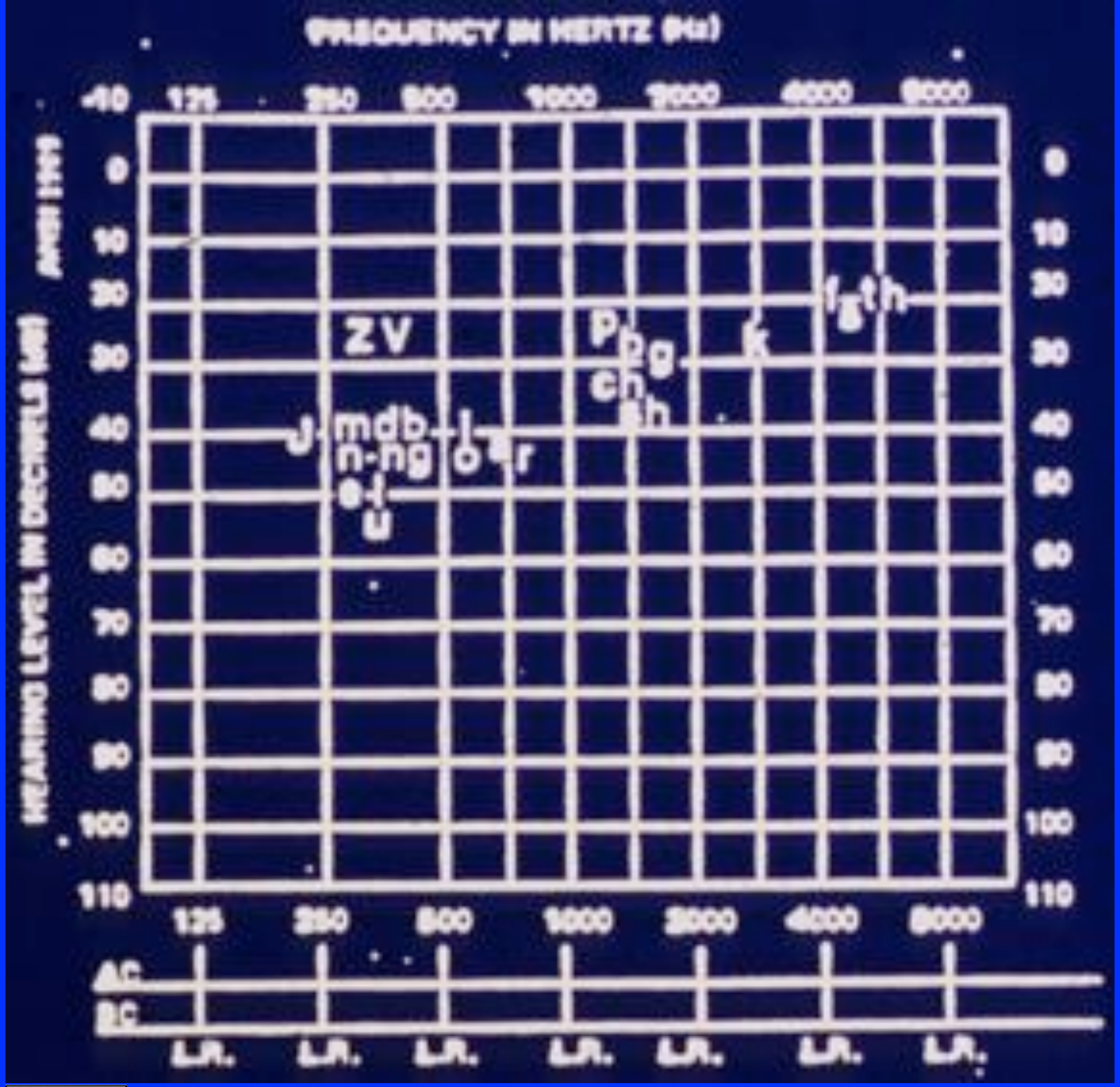
Philip Zazove has no financial or personal stake in a company related to any of the topics listed herein.

What Does The Word "Deaf" Mean To You?

- World Health Organization Definition
  - So severe that amplification doesn't help
- Oliver Sachs Defines Three Types of hearing loss:
  - Not need amplification
  - Can only communicate with amplification
  - Can't amplify enough to enable to hear others

American Speech and Hearing Association (ASHA) scale

Degree of Loss	dB loss
Normal	<27
Mild	27-40
Moderate	41-55
Moderately severe	56-70
Severe	71-90
Profound	>90



Wide Spectrum of Hearing Loss:

- A. Type of loss
  1. Sensorineural
  2. Conductive
  3. Mixed

- B. Specifics of loss
  1. Frequencies involved
  2. Intensity of Loss
  3. Whether one or both ears

Wide Spectrum of Hearing Loss:

- C. Age of loss
  - Prelingual (11%)
  - Postlingual but pre-educational
  - Post-educational but prevocational (25%)
  - Post-vocational (includes presbycusis; largest % of people with hearing loss)

Wide Spectrum of Hearing Loss:

- D. Even if define type and specifics, hearing loss defies categorization

"Some individuals with mild hearing loss many experience substantial disability and handicap, whereas others with moderate hearing loss may not exhibit any form of disability or handicap."
(Bess 1989)

Prevalence of Hearing Loss

- One in ten Americans has a “significant” hearing loss (defined as a sensorineural loss of 35dB or more in either ear)
- Hearing Loss is the second most common disability in the United States

Prevalence of hearing in the civilian, non-institutionalized population of the United States*

Age (Years)	Prevalence (%)
Newborn	0.2
Under 18	5
18-44	7
45-64	18
65-74	28
75 and over	45
All Ages	~10

*NHIS, ASHA, and other data

More Common In:

- North Central and Western United States
  - Less common in Northeast
- Men:Women = 118:100
- White race
- Older persons
  - Baby boomers will greatly increase # patients

Demographics

- Younger Ages

  Incidence is changing due to advances in medicine

  - Vaccines reduced meningitis prevalence while antibiotics and PE tubes reduced otitis media complications
  - NBICU survivors have increased risk
  - Traditionally: 50% of childhood hearing loss is due to specific syndromes, infections, drugs and other known causes; the remaining 50% has been considered idiopathic

Genetic Causes of Hearing Loss

- We now have a better understanding of the 50% idiopathic group

  ~50% of non-syndromal, autosomal recessive, congenital, hearing loss are due to genetic polymorphisms:

  - » Connexin 26 and 30 are greatest prevalence
  - » MT-RNR1 (A1555G) and MT-TS1

Prelingual Hearing Loss

- Average age of diagnosis of a congenital hearing loss is 2-3 years old

    1. Slowly detecting earlier over time
    2. 75% are detected by family, not by physicians
    3. Results in delay in teaching these babies language

Prelingual Hearing Loss

4. Nationwide movement to screen infants for this

   a. Over 40 states mandate newborn screening – NOT Michigan
      - Still, over 95% of Michigan babies ARE screened

   b. Done by Otoacoustic Emissions/Acoustic Brainstem Response
      - Is effective – 57% detection by age 10 mos vs. 14% by M.D./family

   c. Prevalence is 1.86/1000 births

   d. Joint Commission Goal: screen all infants by 3 months and if abnormal, begin all intervention by 6 months

Prelingual Hearing Loss

- The major unknown about universal screening:

  Does early dectection IMPROVE outcomes?

High risk infants:

1. Admission to NBICU
2. Family history of childhood hearing loss
3. Congenital infections associated with hearing loss, e.g. TORCH
4. Craniofacial anomalies including cleft palate
5. Birth weight under 1500 grams
6. Hyperbilirubinemia requiring exchange transfusion

High risk infants' criteria:

7. Ototoxic drugs in more than usual doses
8. Bacterial meningitis
9. Severe asphyxia at birth
10. Prolonged mechanical ventilation > 9 days
11. Stigmata associated with hearing loss
12. Extracorporeal membrane oxygenation-ECMO
13. Certain ethnic groups (e.g., Pakistani)

High risk infants' criteria:

Only 2-10% of infants with these high risk criteria will be found, upon undergoing screening, to have a significant hearing loss

The background rate of hearing loss in the general infant population is at most 1%

"Groups" of Hearing Loss Types

1. Hard of Hearing – the most common, about 90%. Is the "silent" majority.

2. deaf – profound hearing loss who use oral English; majority of those with profound loss

3. Deaf – profound hearing loss who prefer American Sign Language, belong to Deaf Community

4. Other types of sign and oral languages

Communication

- The major issue in the life of d/Deaf and hard of hearing people is communication with the rest of the world

- Once again, **the major issue** for d/Deaf and hard of hearing persons is communication with the rest of the world

Things the Average Students Do

1. Hear the teacher
2. Hear their classmates in front, behind and all around them
3. Hear and participate in class discussion
4. Hear the educational film presented in class
5. Hear the principal over the public address system
6. Hear the visiting speaker invited for that period
7. Hear the guide on the class field trip
8. Hear the radio or television program assigned to the class

Things the Average Students Do

9. Hear the exchange of friendly chit-chat at recess
10. Hear the quick peer interaction when going down the hall between classes
11. Hear the news and gossip during lunch hour
12. Hear the "sum-up" on the walk home at day's end
13. Hear the student body government meeting debates
14. Hear all of the other countless items that come almost as if by osmosis and of which every one is practically unaware

Things the Average Students Do

"The simple fact is that the deaf child does not hear these."

Mervin Garretson, 1977

d/Deaf learn language differently

1. It is critical that all learn a language before age 3
2. Deaf Community is a certified minority group with its own:
   A. Language – American Sign Language
      1. Different from English/Signed English – spoken or written
      2. Unique syntax, grammar, idioms
   B. History
   C. Traditions and Beliefs
   D. Self-contained group mentality

How Deaf people may write English

"HI I M HERE GA dr z here ga GOOD I HAD HATE TO MY HEAD LIKE TO SURRXX SUFFER HURT YESTERDAY AND TODAY I GOT FEEL JERK MY MIND SO UNDER TO EYES SO DR EYES GIVE ME THAT MDINCE NAME IS DOXYCYCL HYC 100 MG FOR MY OPEN AIR BY PLUG GLAND OIL SO WELL I DON'T LIKE TOO MUCH MEDINCE PLUS BED AND TODAY AROUND TOO RNMN EARLY EAXX PIERODS FRIS OF JAN AND HOW THIS WEEK I HATE DESTORY TO MY BED GA……"

From a Focus Group:

- Participant: Doctors are patient with people who are blind or in wheelchairs but they are not as patient with us deaf people.
- Facilitator: Why do you think that is?
- Participant: Well, maybe it's because we can't write. The people in wheelchairs and those who are blind can speak, but we can't, and we have to write back and forth with the doctors."

deaf/hard of hearing vs. Deaf

3. deaf and hard of hearing (i.e., non-Deaf) learn oral language, although often only by sight

   A. 90% of all D&HH persons are in this category
      - In this country, usually learn English

   B. Are often embarrassed about their hearing loss and try to keep it concealed

Deaf vs. deaf

- Deaf refers to members of the Deaf community:
  - Most of them use the local sign language
  - Are proud/public about their hearing loss
  - Want their kids to be Deaf
- deaf refers to everyone else with a profound hearing loss:
  - Most of them prefer the local oral language
  - Most keep quiet about their hearing loss
  - Want their children to be hearing

Interpreters help communicate with society

- Interpreters must meet certain specifications
  - Code of ethics
  - Confidentiality
- Interpreters can be sign or oral
- Different levels of interpreter expertise
  - Medical interpreting needs highest level

"I find out if there is an interpreter provided and if there's none there, then I leave …I don't want to struggle with them (the doctors)."

"…it got confusing, so I asked for an interpreter, and I got one amazingly, oh my gosh! I got lots of information, it felt spontaneous, even the nurse told me information that was useful; when writing before, (I) never got that information. I realized doctors are complicated, but by forcing doctors to write, it made the doctor limited in the information that was given to me."

Americans with Disabilities Act (ADA)

- This law states that:
  - D&HH persons have a right to an interpreter at the PHYSICIAN'S expense
  - The patient must request the interpreter AHEAD of time

Socioeconomic impact of a hearing loss

Lower than average hearing person

A. Education (1989 data)
   1. Read at 6th grade level
   2. Only 13% graduate college

B. Economic
   1. 45% with full-time job, usually lower paying ones
   2. 50% with family pretax income <= $25,000

Psychosocial Aspects

A. Hearing parents of d/Deaf children

1. Traditionally thought to react like those facing death, i.e., shock, denial, grief
   - Now know many don't
2. Strong cultural role exists
   - E.g., ror Latinos, a child with a disability is considered a "failure" of the parents, especially the mother
   - Thus shame and guilt often come into play

Psychosocial Aspects

B. Hearing children of d/Deaf parents:

- Called CODAs
  - » Increased responsibility compared to peers
- Sometimes ambiguous identity
  - » Straddle both Deaf and Hearing worlds
- Similar in some ways to children of alcoholic parents

Psychosocial Aspects

C. Hard of hearing persons:

- Feel in-between, lost and not understood
- Have difficulty communicating and convincing people of the huge impact of their hearing loss
- Often withdraw from society

Psychosocial Aspects

D. Societal stigmas of hearing loss of any extent:

1. Reluctance of family to acknowledge hearing loss
   - Often downplay hearing loss, believes patient deliberately doesn't listen
   - Affected person gets a negative self-imag
2. Patients often conceal hearing loss
   - Refuse to wear hearing aids
   - Won't ask for assistance or acknowledge hearing loss

Psychosocial Aspects

E. Workplace implications of a hearing loss:

- Object of jokes or labels (“deaf one”)
- Restricted opportunities/advancement
- Suspicions that person takes advantage of hearing loss
- Resist accommodations despite legal obligations to do so

Put down of d/Deaf people

”…there seems to be a bit of a stigma with being deaf…a lot of the people that I work with think that because I have gone deaf I have suddenly turned stupid as well, over this last year I have certainly found out who my friends are, but it has been hard and hurtful that people who I thought were my friends didn’t want to know about someone that is a bit different. I feel that you might have found the same and it is very hard to stay positive, but take each day one at a time and remember that you are just the same as the next…Sure sounds like deaf people have a lot of the same experiences being treated like you are dumb, and finding out who your real friends are: this is something I have heard from other people also, but that doesn’t make it any easier to swallow!”

Hearing Loss vs. Dementia

Alzheimer's

Depression/Anxiety/Disorientation
Reduced Language Comprehension
Impaired short-term memory
Inappropriate psychosocial response
Loss of recognition (Agnosia)
Denial/defensiveness/negativity
Distrust, suspicious of other's motives

Untreated Hearing Loss

Depression/Anxiety/Social Isolation
Reduced speech comprehension
Reduced cognitive input into memory
Inappropriate psychosocial response
Cognitive dysfunction
Denial/defensiveness/negativity
Distrust, feel others talking about them

Chartrand 2005

Health Care Utilization and Health Status of D&HH persons

A. Have trouble communicating with doctors:

1. Lass et al found that:
   a. 44% of college educated Deaf had trouble communicating
   b. Over half of these people write with physicians
      - Problem because ASL is different from English
      - Many don't know common terms such as nausea, allergic
      - 59% didn't understand written notes about their meds
2. McEwen found:
   a. Deaf persons are greater risk than other non-English speaking persons for miscommunication with their physician

"…All I want is to be able to go to the emergency room and please, them knowing what to do. Take care of me like anybody else. I have to go on in and they don't communicate with me and they start touching me all over my body. It is very distressing."

National Health Interview Survey Data for D&HH as a group

B. Physician Visits

# Annual Physician Visits	All Levels of Hearing Loss	Hear Normally
No visits	17.2	25.7
1-5 visits	52.8	57.9
6 or more visits	30.0	16.4

National Health Interview Survey Data for D&HH as a group

B. Annual Bed Days

# Annual Bed Days	All Levels of Hearing Loss	Hear Normally
No bed days	51.4	54.9
1-7 Bed Days	27.2	34.9
8 or more Days	21.3	11.0

National Health Interview Survey Data for D&HH as a group

B. Self Health Assessment

Assessment of Health Status	All Levels of Hearing Loss	Hear Normally
Excellent	29.9	50.1
Good	38.9	38.6
Fair	21.0	8.9
Poor	10.1	2.4

Health Care Utilization and Status

C. Mortality same as hearing persons:

Study	Year	D&HH/Hearing Lifespan
Beck	1943	0.75
Schein	1974	1.33
Purohit	1990	1.00

Health Care Utilization and Status

D. Physicians with their D&HH patients:

- Feel less comfortable with them
- Believe understand diagnosis and treatment less
- Often don't use interpreters even though agree these help with communication
- Perform fewer interventions on D&HH patients

Health Care Utilization and Status

E. Health Behaviors of D&HH Persons

1. Smoke, drink and use drugs less than hearing persons
2. Attitudes about physicians:
   - Don't like visiting doctors because of difficulties communicating
   - Feel are not treated as a person by them
3. Deaf community has twice the rate of domestic violence as hearing society

Health Care Utilization and Status

F. Deficient Knowledge Base

1. Preventive Medicine
   - » Know less about current recommendations
2. Disease Understanding
   - » More likely to think can acquire AIDS from toilets and to be more intolerant of people with AIDS
3. Interventions to improve this are unclear
   - » Provision of sign language interpreters, captions on a video did NOT improve knowledge for a group of Deaf persons

Health Care Utilization and Status

Specific Cultural Beliefs of deaf/HH and Deaf

» Most deaf and Hard of Hearing Persons

- Favor cochlear implants or pre-conceptual genetic testing for deafness
- Are embarrassed about their hearing loss and keep quiet about it
- May be resistant to talking about this

» Most Deaf persons

- Oppose cochlear implants and pre-conceptual genetic deafness testing
- Are proud of their deafness and are public about it

Comparison of Deaf vs. deaf/HH

Deaf	deaf/Hard of Hearing
ASL primary language	English primary language
Proud	Embarrassed
Start with main point	Work up to main point
Repeat recommendations	Repeat recommendations
Often marry Deaf spouse	Marry deaf/hh or hearing
See physicians less often	See physicians more often
Written English poorly	More likely to use English
Sign interpreters/CART	Oral interpreters/CART
More likely to be Connexin +	More likely to be other cause
Usually lose hearing young age	Often lose hearing older age

Americans with Disabilities Act (ADA)

A. Physicians furnish and pay for auxiliary aids/services

- including interpreters if necessary to ensure effective communication
- Interpreters cost >=$40/hour
- Family friends are not appropriate for interpreting

B. Patients decide what aids they need

- must tell physician ahead of time in order for the physician to be liable
  - Patient can't just walk in for their appointment and expect office to find an interpreter

"I was still awake and the doctor kept going and pushing me and pushing me down and telling me, you know, just 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.' "

Interacting with D&HH Patients

DO

1. Look directly at the d/Deaf person when speaking
2. Make sure there is good light in the room
3. Enunciate clearly but don't exaggerate
4. Talk to patient, not interpreter
5. Be prepared to repeat information several times
6. Be aware of culture, communication issues

Interacting with D&HH Patients

DO

7. Know the differences between deaf, Deaf and hard of hearing
8. Be aware of legal obligations under ADA
9. Consider the possibility of hearing loss in WCC visits (at least until we have routine newborn screening in all states)
10. Understand that many D&HH patients have lower knowledge about health care than hearing person
11. Consider domestic violence in Deaf families

Interacting with D&HH Patients

DO NOT

1. Over-enunciate
2. Write with patients unless they tell you they are okay with that
3. Talk to the interpreter rather than patient
4. Whisper or speak asides to nurse/interpreter
5. Assume the patient understands without double-checking
6. Talk with a window or bright light behind you
7. Assume the patient prefers a certain language

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