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Adult Perceptions of Hearing Status and Options: Professionals Facilitating a Life-Long Hearing Journey, in partnership with American Cochlear Implant Alliance

Donna Sorkin, MA, Executive Director, American Cochlear Implant Alliance

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Donna L. Sorkin, MA

Donna Sorkin, MA is the executive director of the American Cochlear Implant Alliance, a non-profit organization working to expand access to cochlear implants through research, advocacy and awareness. Prior to joining ACI Alliance in late 2012, Donna was Vice President of Consumer Affairs for Cochlear Americas where she led public policy initiatives and activities aimed at the broad life needs of cochlear implant users including insurance practices, habilitation, and educational needs of children with cochlear implants. Ms. Sorkin was previously the executive director of Hearing Loss Association of America and the AG Bell Association for the Deaf and Hard of Hearing. She has served on federal, corporate and university boards including the U.S. Access Board, the National Institute on Deafness, NIH and Gallaudet University. She holds a Masters from Harvard's Kennedy School.

Five Part Series on Adult Assessments in Hearing Healthcare

- Adult Assessments: Working Across the Continuum
- Roles of Audiologists and Dispensers Working with Hearing Aid Users on CI Candidacy
- Utility of the New CI Quality of Life Instruments to Personalize and Improve CI Care
- Adult Perceptions of Hearing Status and Options: Professionals Facilitating a Life-Long Hearing Journey
- Optimizing Outcomes in Hearing Technology: Hearing Aids and Implantable Devices

Why another organization in hearing health?

- Membership organization focused on cochlear implantation and access to care
- Members are audiologists, physicians, speech pathologists, educators and others on CI teams + consumers/parents, advocates, hearing aid specialists
- Website designed for those in and out of CI
- Highly collaborative with other organizations

Welcome your involvement!

www.acialliance.org

https://www.facebook.com/ACIALLIANCE.ORG/

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AMERICAN COCHLEAR IMPLANT ALLIANCE

Research. Advocacy. Awareness.

American Cochlear Implant Alliance

- Mission: Advance access to the gift of hearing provided by cochlear implantation through research, advocacy and awareness
- Address factors contributing to underutilization of cochlear implants
- Improve awareness regarding candidacy and outcomes

Disclosures

- **Presenter Disclosure**: Financial: Donna Sorkin is employed by the American Cochlear Implant Alliance. She received an honorarium for this course. Non-financial: Donna Sorkin wears a cochlear implant. She has served on federal, corporate, and university boards, including the U.S. Access Board, the National Institute on Deafness, NIH, and Gallaudet University.
- **Content Disclosure**: This learning event does not focus exclusively on any specific product or service.
- **Sponsor Disclosure**: This course is presented by AudiologyOnline in partnership with the American Cochlear Implant Alliance.

Learning Outcomes

After this course, participants will be able to:

- List common concerns about loss of residual hearing, typical speech perception gains, music appreciation, quality of life changes, and future options for adults who receive cochlear implants.
- Discuss health insurance coverage of cochlear implants and compare such coverage to that of traditional amplification.
- Explain cochlear implant surgery to address fears or misconceptions that may prevent patients from moving forward.

Poll: Who is here today?

- Audiologist who works primarily on cochlear implants
- Audiologist who works with hearing aid patients
- Audiologists who works with both CI and hearing aids
- Other audiologist
- Hearing Aid Instrument Specialist
- Speech Language Pathologist
- Other Clinician or Educator
- Anyone else!

Agenda

1. Cochlear Implants within the Continuum of Hearing Healthcare
2. Perceptions, Misconceptions, Fear
3. Research Relevant to Common CI Fears
4. What candidates and recipients say about what would have helped them through the CI journey

Poll: What do you think accounts for low utilization of cochlear implants?

a) Lack of awareness/understanding of candidacy and outcomes

b) Perception that most insurance policies don't cover CI

c) Patients feel that they are doing ok with hearing aids

d) There are better options for severe to profound hearing loss that don't involve surgery (such as high-tech hearing aids and remote microphones)

e) Concerns about the surgery

Top Concerns Adults had about moving forward with a CI (Adult Survey)

1. Concerns about the surgery
2. Didn’t want to lose my residual hearing
3. Felt I was doing ok with my hearing aids
4. Thought I would not enjoy music
5. Wanted to wait for the technology to improve
6. Perception that CI wasn’t covered by health insurance

Source: SurveyMonkey conducted February-March 2023

Top Reasons Adult CI Candidates Chose NOT to Move Forward

1. Don’t want to lose my residual hearing
2. Wish to wait for the technology to improve
3. Getting along ok with hearing aids
4. Concerns about the surgery

Source: SurveyMonkey conducted February-March 2023

Less Frequently Mentioned as Concerns

- Felt that I would not enjoy music
- Wanted to wait for the technology to improve
- Concerned about the way the technology looks on the head

According to CI Clinicians, why some adults don't move forward

- Had other medical issues that took precedence
- Concerns about the surgery
- Didn't want to lose residual hearing
- Felt that they were doing ok with hearing aids
- Didn't like the way the CI looked on the head (i.e., cosmetics)

What does the research say about these concerns?

Concerns about the surgery

- CI is not brain surgery!
- Typically performed out-patient (1-2 hours)
- Safe and effective
  - Overall rate of major complications: 2-3% (similar or better than other surgeries): Lane, *Larynoscope* 2020
  - Typical major complications: migration of receiver or electrode array requiring 2nd surgery
  - Facial paralysis and infection less common
- Short Term (temporary) effects may include
  - Dizziness/balance issues, tinnitus, taste disturbance
- Resources for patients on ACI Alliance website
  - https://www.acialliance.org/page/Surgery

Loss of residual hearing

- Early on, CI surgery meant patients lost residual hearing in the implanted ear
- No longer the case that patients lose all hearing
  - ”Soft” surgery and intraoperative adjustments during insertion of the electrode array help preserve existing hearing
  - Internal CI devices designed to support that goal
- Electroacoustic devices combine CI and hearing aid use in same ear providing improved hearing/QoL
- Studies of CI use show that many patients have at least some residual hearing
- Patients almost always gain much more than they lose

Ref: Gantz et al. Clinical perspective on hearing preservation in cochlear implantation, University of Iowa experience. *Hearing Research*. 2022; Adunka. Clinical Utility of Residual Hearing in the CI Ear, Clinical Trials.gov, 2022.

Getting by with hearing aids

- Common reason for not going forward
- *I'm doing ok with my hearing aids, assistive devices, captioning, lipreading, hearing dog ….*
- People don't realize how poorly they are doing with hearing aids alone
- Don't know how much better they will do with a CI
- Can still using hearing aid on the contralateral ear
- FEAR of the unknown
- Human nature ➔ keep doing what you're doing

What recent research showed

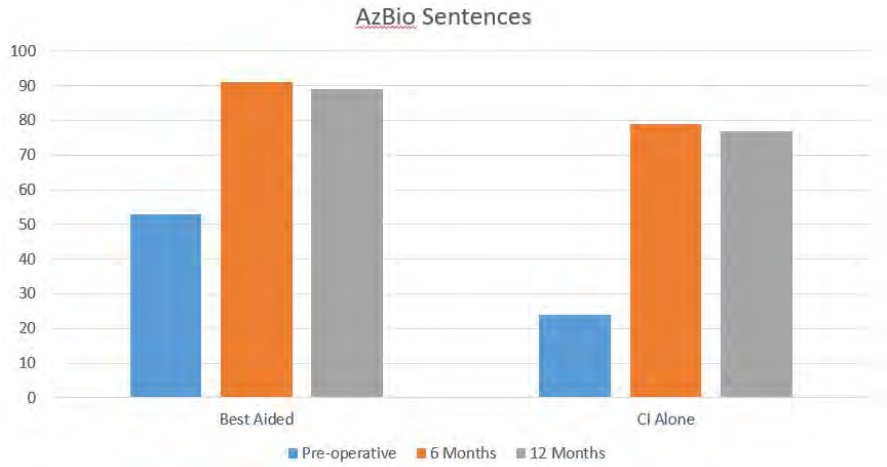
- 34 Medicare beneficiaries (Median age 73.6)
- Preop (baseline) sentence scores in best aided 53% bilaterally, 24% in ear to be implanted
- 12 months post CI: 89% bilaterally, 77% in CI ear alone
- Median change in best aided and CI alone: 36%, implanted ear improvement: 53%
- Study submitted to CMS leading to revision in Medicare candidacy criteria (Sept 2022)

Ref: Zwolan et al. Assessment of Cochlear Implants for adult Medicare beneficiaries aged 65 years or older who meet expanded indications, *JAMA Oto*, 2020.

Assessment of CI for Adult Medicare Beneficiaries Study (for NCD)

AzBio Sentence Scores

Measure	Baseline Median (Min-Max)	6-month Assessment Median (Min-Max)	12-month Assessment Median (Min-Max)
AZ BIO SCORE BEST AIDED	53 (26 to 60)	91 (25 to 100)	89 (36 to 100)
AZ BIO SCORE CI ONLY	24 (0 to 53)	79 (0 to 99)	77 (13 to 100)



Thought I would not enjoy music

- Conventional wisdom ➔ CI recipients don't enjoy music
  - Pitch isn't handled well by CI ➔ pitch determines melody
- New conventional wisdom ➔ many recipients enjoy music
  - Having words to songs helps
  - Rhythm may be near normal
  - Practice, know how to listen, keep expectations appropriate
  - Music is about enjoyment

Ref: https://www.acialliance.org/page/CIMusic. AO course: https://www.audiologyonline.com/audiology-ceus/course/adults-enjoy-music-cochlear-35602

Waiting for the technology to improve

- Most enhancements via the external sound processor
- Internal device designed to last a lifetime
- Upgrades without needing another surgery
- 7 processors since original surgery in 1992 with insurance coverage with co-pays

+ 3

Enhancements including:

- Size, configuration (e.g., off the ear)
- Larger grab of sound
- Bluetooth for phone, TV, computer
- Improved noise programs

Health Insurance Coverage

- Because hearing aids are not typically covered, people may assume CI is also not covered
- Cochlear implants are covered by ~90% of private health insurance plans, Medicare, Medicaid everywhere for children and in most states for adults, VA, Tricare, ACA Plans
- There are co-pays just as there are for other health interventions; these vary by insurer and by plan
- Source: https://www.acialliance.org/page/Insurance

What was it like in 1992?

- Progressive hearing loss
- Hearing aids not helping
- High communication job
- ADA beginning to impact societal perspectives
- No Internet!
- More openness about hearing loss
- Social events and work challenging
- Not much awareness about CI
- “Re-invent” my life

Why and what helped me move forward

- Getting little auditorily from hearing aids
- Exhausted all the time
- Challenges at work and social events
- No email or texting ➔ communication was complicated
- Audiologist suggested I explore CI
  - Gave me the names of patients who had gotten CI
  - Supported me in the journey
- My internist explored CI candidacy, helped me find a CI center and called the surgeon
- Great family support
- Friends who cheered me on

What happened?

- Early cochlear implant outcomes more variable than today
- Then for adults: Longer periods of deafness, less residual hearing
- Key impacts for me (then and now)
  - Work
  - Social/Family Interactions
  - General Health (reduced stress?)
  - Quality of Life Overall
- Continued benefit from technology improvements w/out additional surgery
- Using 7th sound processor
- Unlimited opportunity to contribute

Parade Magazine, January 1995

What adults say would have helped them through the journey

- Meeting others with cochlear implants
  - In-person rated #1
  - Virtual helpful #2
- Having access to research-based information in format that is accessible to me and my family
- Greater availability to clinicians who could address my concerns and answer questions
- Kindness

Empathy matters

Some great resources for you and your patients

- American Cochlear Implant Alliance
  - www.ACIAlliance.org
  - Steps to a CI, Q&As
  - Videos on key concerns (i.e., surgery, insurance)
  - Stories by CI recipients and family members
  - Tuesday Talks cover candidacy, surgery, mapping the device, rehabilitation
  - Coming soon: Virtual meet up with a recipient
- Online communities: CI Experiences Facebook group www.ACIAlliance.org

Thank you!

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