Cochlear Implants with Lack of Follow-Up: An Ethical Dilemma

Maria Leno, Au.D.  Laura Rickey, Au.D.
Anita Jeyakumar, MD MS FACS FAAP
Akron Children’s Hospital
Akron, OH
Disclosures

• None
CI Candidacy

- FDA: 12 months of age or older
- Bilateral severe to profound sensorineural hearing loss
- Limited benefit from appropriately fit hearing aids
- Lack of progress in auditory skill development despite appropriate intervention
- No physical contraindications for placements of the implant
- Medically cleared to undergo surgery
- **Realistic expectations and commitment to follow-up appointments**
Communication Options for CI Candidates

- Listening and Spoken Language
- Cued Speech/Language
- American Sign Language/Bilingual-Bicultural
- Total Communication
**Pre CI**
- 3-6 month hearing aid trial
- CI Evaluation
- Speech Evaluation
- Otolaryngology Evaluation
- Pre-surgical Visit
- Surgery

**Post CI**
- Post-op Otolaryngology visit
- Initial Activation
- 1-2 week post activation
- 1 month post activation
- Minimal every 3 months for at least year 1
- AVT weekly or biweekly appointments
What happens if they are noncompliant with recommendations?
The Problem…

No show/cancelled appointments + Low wear time

= Poor performance and no true language
The Barriers…

- Lack of understanding the need for therapy, programming, and consistent use of device(s);
- Lack of local resources available to the families
- Accessibility to follow-up (e.g., transportation, time off work, financial resources).
- Family chaos and disorganization
- Lack of trust in healthcare professionals
- Impairment of caregivers
- Caregivers belief system
- Child’s attitude and behavior
- Variable caregivers

Jenny, C., 2007
Frist steps – Addressing Barriers

• Re-evaluate goals
• Discuss barrier with family
• Involve appropriate professionals
• Discuss again importance of follow-up

They still don’t show!!!
Affects more than just the patient

- Appointment slots could be filled by other children in need
- Low productivity for providers

What do we do?
Let’s review

• Family chose cochlear implants
• Family chose spoken language
• Barriers have been addressed
• Family continues to choose not to follow-up

Medical neglect?
Neglect

- The failure of a parent or other person with responsibility for the child to provide needed food, clothing, shelter, *medical care*, or supervision to the degree that the child’s health, safety, and well-being are threatened with harm

Medical Neglect

- Specifically includes failure to heed obvious signs of serious illness or failure to follow a physician’s instruction once medical advice has been sought
- Either of these situations can be fatal in some cases or can lead to chronic disability
Factors necessary for Medical Neglect

- A child is harmed or is at risk of harm because of lack of health care;
- The recommended health care offers significant net benefit to the child;
- The anticipated benefit of the treatment is significantly greater than its morbidity, so that reasonable caregivers would choose treatment over non-treatment;
- It can be demonstrated that access to health care is available and not used;
- The caregiver understands the medical advice given.

Jenny, C., 2007
Noncompliance = Medical Neglect
Proposed Protocol

- After multiple no shows/cancellations and lack of progress
  - Call Social Work; discover barriers
  - Address barriers

- If no shows/cancellations continue along with lack of progress/low wear time
  - Report Medical Neglect to County Children Services
  - Maintain a line of communication on progress of the case
What’s next

• Further research
  • Track to see if proposed protocol is beneficial
  • Complete a detailed survey to obtain information on the policy of other centers
Resources


