G. Paul Moore Symposium 2022

Lilach Saperstein, Au.D.
Disclosures

Financial
✓ Receiving an honorarium.
✓ Parent coach and facilitator of "Connect & Advocate" online group program.

Non-Financial
✓ Host of the "All About Audiology" Podcast
✓ Facilitator of the H.E.A.R (History, Emotions, Advocacy, Reconnect) online virtual retreat.
Parent Counseling in Audiology

(morning session)

9:00 AM – 10:30 AM: Lecture
10:30 AM – 10:40 AM: Break
10:40 AM – 11:30 AM: Lecture
11:30 AM – 11:40 AM: Question and Answer Session

- Classify categories of information that need to be transmitted to the family.
- Identify the possible family states of retention throughout a counselling session.
- Differentiate between productive counselling questions and detrimental practices.
Educational Media and Content
(afternoon session)

12:05 PM – 1:30 PM: Lecture
1:30 PM – 1:40 PM: Break
1:40 PM – 2:40 PM: Lecture
2:40 PM – 2:50 PM: Question and Answer Session

- Contrast the **types of media**, ie. old media vs new media.
- Detect the **source of information** and credentials of the author/account owner.
- Illustrate the **power and reach** of professionally created content.
Our audiologist didn't explain anything. They put stickers on my baby's head and then told us he was deaf. I was in shock. It didn't feel real.

V, mother to R, 6 yrs old
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What is the patient/family journey with audiology?

- Newborn Hearing Screening Referral
- Parental Concern (self referral)
- Pediatrician/ ENT / Early Intervention
- Routine visit
- Pre-K requirement

Prior knowledge
- Expectation
- Readiness
What emotional states might the family be in?

Confusion  Relief
Anger      Exhaustion
Worry      Fear
Disbelief

What do they need most? **information or support**

Ask them what they need.
Types of Counseling

- Informational counseling
- Shared decision-making
- Supportive counseling
- Providing support resources
I was worried about whether my son had CMV, how we could test for that, what other disabilities he might be facing, not his audiogram.

A, mother to G, 2 years old.
Types of Counseling

- Informational counseling
  - Explanation of audiogram, type, degree, configuration of hearing loss, hearing aids/BAHAs, cochlear implants, FM systems
  - Referral to interventionists (SLP, OT, PT, edu psych, etc.)

- Shared decision-making

- Supportive counseling
  - Acknowledgement of feelings, concerns, specific questions.
  - Scheduling future appointments, providing further contact method.
  - Referral to support group, peer-to-peer support, mentors, & community events.

- Providing support resources
Foster Good Rapport

Introduce yourself, with credentials and the purpose of the session.

Establish your goals for the session. Confirm understanding.

Ask: What are you hoping to get out of today’s appointment? now, LISTEN.
Types of Audiology Appointments

- Test hearing, initial or follow up
- Evaluating balance, auditory processing
- Counseling on previous results
- Counseling on impact of results
- Referral for further workup or medical treatment
- Orientation of devices
- Programming of hearing aids/MAPping of cochlear implants
- Annual follow ups

Does the family know what KIND of appointment they are coming in for?
1. **Reading level** is too high.

2. Information is not easily recalled, when given **verbally OR in written form**

3. Adding **visual and multimodal components** improves the success of parental education.

"Pictograms and videos were the most effective visual aids."

(Mbanda, 2021)
Social Story

Resources to prepare for the appointment

https://www.youtube.com/watch?v=l2PDPRfCm3M
https://www.youtube.com/watch?v=-8sP7l7EH1c
https://www.connecticutchildrens.org/search-specialties/audiology/expect-play-hearing-test-glastonbury/
Giving Clear Instructions
Make sure the parent knows what their role is.

ABR- Auditory Brainstem Response

Tympanometry
"What I would like best of all, is when I turn around and they tell me, ‘They couldn’t hear below 65’. ‘That’s where we are on the screen, you’re right.’ They’re part of the diagnosis, they are part of the test, they are part of the assessment.

It’s not that my back is to you and in the end, I’m going to turn around and show you a piece of paper and this is it. This is where you have commitment and you have knowledge and you have buy-in by the parent.

Nothing made me more satisfied, as hard as it was, to turn around and have them (the parents) tell me the result before I could show it to them."
How does hearing work?
What does it mean?!

**frequency** - pitch - like the keys along a piano

**intensity** - volume - how loud or soft sounds are

Use layman's terms, simple language!

What kinds of sounds do they have access to?
How loud do sounds have to be for them to hear it?
How will this affect their spoken language development?
Hearing Levels

Frequencies (Hz)

Volume (dB)

-10

NORMAL HEARING

MILD HEARING LOSS

MODERATE HEARING LOSS

MODERATELY SEVERE HEARING LOSS

SEVERE HEARING LOSS

PROFOUND HEARING LOSS
## About their child's hearing

<table>
<thead>
<tr>
<th><strong>Type</strong></th>
<th><strong>Causes/Etiologies</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Conductive,</td>
<td>Known or unknown,</td>
</tr>
<tr>
<td>sensorineural,</td>
<td>congenital or acquired</td>
</tr>
<tr>
<td>mixed</td>
<td></td>
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<table>
<thead>
<tr>
<th><strong>Degree</strong></th>
<th><strong>Uni- or Bi- lateral</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild, moderate,</td>
<td>One ear or both,</td>
</tr>
<tr>
<td>mod-sev, severe,</td>
<td>symmetrical?</td>
</tr>
<tr>
<td>profound</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Configuration</strong></th>
<th><strong>Stable or progressive</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Sloping, flat,</td>
<td>Family history,</td>
</tr>
<tr>
<td>cookiebite, rising</td>
<td>genetic testing</td>
</tr>
</tbody>
</table>
Check for understanding

1. Did you understand the way we got today’s/composite results?
2. Do you understand what these results mean for your child?
3. What questions do you have at this point?

This is a fork in the conversation.

Before moving on to treatment/interventions/referrals, check in with the family.

Do they need more time to process or understand their child's test results and hearing status?
Understanding ≠ Acceptance

- Cycle of Grief
- Denial
- Anger
- Bargaining
- Depression
- Acceptance
Middle Ear Effusion

The value of a photo!

Follow up is vital
Progression and long-term effects
What do we do about it?

Make referrals and when possible, have people contact them!

1. Language Development: SLP referral, Deaf mentor
2. Ear Health: Imaging studies, ENT referral
3. Device Options: HA, BAHA, CI, FM system
4. Educational Option: EI referral, school contacts
5. Liaison with pediatrician
Device Orientation

Process
From device selection-fitting-programming-acclimatization-rehabilitation

Realistic expectations
Risks, benefits, drawbacks, common complaints, cost, timeframe

How it works
Who is/isn't a candidate for this device.
Treatment/Intervention

Hearing Aids
✓ Choosing the device
✓ Making a mold if needed
✓ Initial programming, and "fine-tuning" series
✓ Rehabilitation process - auditory training

Cochlear Implants
✓ Surgery
✓ Initial Activation "switch on"
✓ Series of Mapping appointments
✓ Rehabilitation process - auditory training
Factors that affect CI "success" to consider

- Age of onset
- Stimulation of the auditory system prior to implantation (hearing aids)
- Pre or post lingual
- Overall medical and cognitive development
- Therapy, support, intervention, re/habilitation, consistent mapping.
- Family involvement, motivation
"Knowledge deficit, difficulties to contextualize benefits and risks and fear are some factors that make this process difficult.

...in which the family needs to weigh gains and losses, experience feelings of accountability and guilt, besides overcoming the risk aversion.

Hence, this demands cautious preparation and knowledge from the professionals involved in this intervention.

In our community, if the child wears hearing aids, it will affect her - and her siblings' - marriage prospects. We want to keep it as hidden as possible.

Anonymous
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"Old Media" | "New Media"
<table>
<thead>
<tr>
<th>WEB 1.0</th>
<th>WEB 2.0</th>
<th>WEB 3.0</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mostly Read-Only</td>
<td>Wildly Read-Write</td>
<td>Portable and Personal</td>
</tr>
<tr>
<td>Company Focus</td>
<td>Community Focus</td>
<td>Individual Focus</td>
</tr>
<tr>
<td>Home Pages</td>
<td>Blogs / Wikis</td>
<td>Live-streams / Waves</td>
</tr>
<tr>
<td>Owning Content</td>
<td>Sharing Content</td>
<td>Consolidating Content</td>
</tr>
<tr>
<td>WebForms</td>
<td>Web Applications</td>
<td>Smart Applications</td>
</tr>
<tr>
<td>Directories</td>
<td>Tagging</td>
<td>User Behaviour</td>
</tr>
<tr>
<td>Page Views</td>
<td>Cost Per Click</td>
<td>User Engagement</td>
</tr>
<tr>
<td>Banner Advertising</td>
<td>Interactive Advertising</td>
<td>Behavioural Advertising</td>
</tr>
<tr>
<td>Britannica Online</td>
<td>Wikipedia</td>
<td>The Semantic Web</td>
</tr>
<tr>
<td>HTML/Portals</td>
<td>XML / RSS</td>
<td>RDF / RDFS / OWL</td>
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**Web 3.0** | The "Social Internet"
How do parents use the internet as a source of medical information for their kids?

- Cross-sectional survey of parents of children 0 to 18
- n of 258 parents

- patterns of Internet and social media use,
- parental ratings of the accuracy, reliability
- appeal of information from social media.

Results

Nearly all parents (96%) used social media, with 68% using social media for health information.

Only half of parents discussed information from social media with their physician.

The most common topics included: sleep, mental health, and car safety.

Getting Hearing Aids

Parents have reported a range of challenges such as, frustration in keeping the hearing aids on their child and a lack of confidence knowing how to manage the hearing aids, and they have indicated that they want more learning support (Muñoz, Preston, and Hicken 2014; Muñoz et al. 2016, 2019).
Caring for \textit{hearing aids}:

**MORNING**
- Close Battery Door
- Quick Listening Check
- Place in Child’s Ear
- Confirm Snug Placement
- Sing a Song!
- Get new molds every ~6 months, or as often as your child needs new shoes.
- Molds can be washed with soap and water – separate them from the tubing.
- Do NOT get the hearing aid wet!
- Always keep batteries out of reach of children and pets.
- Keep back up batteries in your car, at school, and at grandma’s house!

**EVENING**
- Remove Hearing Aids
- Open Battery Door
- Wipe Down the Aid
- Clean Tubing
- Place in Drying Chamber

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Evaluating the \textit{hearing aids}

**POR LA MANANA**
- Cierre la Puerta de las baterías
- Prueba de oído rápida
- Póngalo dentro de la oreja de su hijo
- Asegúrese que quedan firmes
- ¡Cante una canción!
- Adquiera nuevos moldes alrededor de cada seis meses, o tan seguido tal su hijo necesita nuevos zapatos.
- Los moldes se pueden lavar con agua y jabón – séquelos de los tubos.
- ¡No moje los auriculares!
- Siempre mantenga las baterías fuera del alcance de los niños y las mascotas.
- ¡Mantenga baterías de repuesto en su carro, en la escuela y en la casa de la abuela!

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**POR LA NOCHE**
- Retire los auriculares
- Habrá la puerta de las baterías
- Limpie el auricular
- Limpie la tubería
- Póngalos en la cámara de secar

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Educating Parents on Daily Hearing Aid Management

- [https://allaboutaudiology.com/hachecklist/](https://allaboutaudiology.com/hachecklist/)
- [https://allaboutaudiology.com/lista/](https://allaboutaudiology.com/lista/)
- 82 parents were randomly assigned to the intervention or treatment-as-usual group.

- The eHealth Program (intervention) was 6 weeks in duration and included weekly phone check-ins and watching a series of eight videos, two videos per week during weeks two through five (available on www.heartolearn.org).

Results

The parents who were in the remote learning group had "more gains in knowledge, perceptions, confidence, and monitoring related to hearing aid management" compared to the group receiving regular care.

It did not affect the hearing aid usage, however there was a significant difference in the overall commitment to HA management and care (ie. troubleshooting tools) in the intervention group.

In the intervention group, 75% of parents indicated they had a good or very good understanding of why it is important to know their child’s hearing aid data logging results, compared to 39% of parents in the TAU group.
Where do parents turn to for information and support?

The internet!

- Parent-to-parent support platforms, i.e. social media.

- Improved their knowledge and understanding of their child’s condition.

- Positively impacted on their decision making, care, and management of their child’s condition.

"However, they reported receiving mixed responses when wishing to engage and share with health care professionals their Internet and social media interactions and information outcomes."

"A digital divide of Internet access was identified in lower educated minorities."

17 studies reviewed.

"health-related Internet use,"
"eHealth," "Internet use for health-related purpose(s),"
"Web-based resource(s),"
"online resources,"

Disease-specific information was used for decision making about treatment, while social support via virtual communities and email were used for informal caregiver emotional needs.

Your podcast has helped me so much. I love all of the different views and subjects that she is able to have guests come on and talk about.

-Listener of the All About Audiology Podcast
INSTAGRAM

1.3 Billion users

500 million use IG DAILY

- Connect with other parents
- Connect with local professionals & institutions
- Connect with online support service providers (international!)
- Have fun, make jokes, memes
PODCASTS
For professionals, for parents, for students...
Deaf and Hard of Hearing Children

Recent Posts
Hearing and Understanding Are Not the Same
It’s Time to Take Audiology Outside of the Box

Subscribe to our emails
* indicates required
Email Address *

Episode 63
All About Counseling in Audiology

3 Types of Hearing
4 Quick Facts About American Sign Language
Audiologist and Speech-Language Pathologists

Dr. Lilach Saperstein
Dr. Sarah Sparks
Listen With Lindsay
by pediatric audiologist
lindsay cockburn, au.d.

Books About Getting Hearing Aids

Zola Gets Hearing Aids
by Marita Snead
Illustrated by Dawn Campbell

Books With Cochlear Implants

Ada and the Helper

Cosmo Gets an Ear

How I Can Hear

Maxx’s Super Ears

Sunny Gets Cochlear Implants

Rally Caps

Sunny’s Bikes

Zola Gets Hearing Aids

Do Cochlear Implants Work?
Episode 25
My Child Has Hearing Loss Now What?

First off, you’re not alone. I’m here to help you. Yes, this is scary. And yes, you’re now on a more challenging journey than the “average” parent. But here’s the truth... in just a few hours from now you’ll have the support and empowerment you need as a parent to begin to make confident choices about your child’s care and your family’s journey with hearing loss. Welcome. I am so glad you are here.
Come say Hi!

https://www.instagram.com/allaboutaudiologypodcast

https://www.linkedin.com/in/lilach-saperstein

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