Symptom Surveillance After Hemispheric Surgery

Auditory Working Group Meeting

May 24, 2024

10:00 AM PST

Attendees: N. McNamara (initiative co-lead lead), F. Musiek (auditory working group lead), M. Jones (patient advocate lead),

Overall, working group members feel this is a vastly under-investigated area and feel strongly that more work and advocacy are needed.

Notes

* M. Jones reviewed the purpose and goal of the initiative
	+ The problem we want to solve: Parents, caregivers, and clinicians do not have a roadmap to navigate medical symptoms and functional outcomes after hemispheric surgery.
	+ The solution: develop recommendations for post-operative symptom surveillance and screening
	+ Our goal:
		- Minimize surprises in chronic postoperative care
		- Prepare clinicians and caregivers for what may happen
		- Provide scaffolding for caregivers to manage medical and functional
		- outcomes through adulthood.
	+ Systematic review has been completed and draft statements prepared
		- [List of all literature with corresponding domains](https://docs.google.com/spreadsheets/d/1GxWaIDtrEcJz9nT6uVPsAcRk47vU-Yy0LtNdgXstTYM/edit?usp=sharing)
		- [List of all proposed statements w/ corresponding literature](https://docs.google.com/spreadsheets/d/1YJ88Zj0AusW8i8j8NC-8bsCzjVkItZzARc3pKfPH0Rg/edit?usp=sharing)
		- [Folder of auditory literature](https://drive.google.com/drive/folders/1qnx_qvLAJeeRyPfphbgmT2DUCFZASZk2?usp=drive_link)
		- M. Jones discussed the desire to model the structure of these recommendations after the paper titled "[Recommendations for Screening Pediatric Psoriasis Co-Morbidities for Primary Care Providers](https://drive.google.com/file/d/19Tfg93OLp_NkIQai8xm7o7WYL1n2DU6T/view?usp=sharing)." She highlighted that this paper is well-organized, with each section having its own table and summary of recommendations, followed by specific recommendations supported by literature and a concluding paragraph.
* F. Musiek discussed that many children post-hemispherectomy likely do not understand the have a central auditory processing disorder and related deficits because they have always had it. The Global Pediatric Epilepsy Surgery Registry indicates that many have hearing compromise before surgery. Patients, parents, and teachers must understand these deficits; it’s likely parents and teachers do not understand the children have auditory deficits as well. Members agreed that education is needed not only for family members and medical providers in other domains, but within the audiology community as well. Members emphasized that there may be confusion in differentiating peripheral vs central auditory processing and that some patients, families, or other professionals may misinterpret a normal audiogram as evidence of normal auditory processing. Members felt that data from the Global Pediatric Epilepsy Surgery Registry could be a very valuable resource moving forward.
* M. Jones clarified that part of the initiative includes knowledge dissemination/translation after the symptom surveillance paper is published. This part of the initiative will take place in 2025.
* Statements were discussed by the group:
	+ Statement A1: Educate all patients about central auditory processing disorders after hemispheric surgery, including but not limited to challenges with sound localization, lateralization, and dichotic listening.
		- Discussion: Brief discussion about this statement. Acknowledgement that inattention, shorter memory issues may be related to central auditory processing deficits. This should also be a red flag for evaluations. Difficult to communicate this issue to parents, caregivers, and other stakeholders. Children should be tested for both peripheral and central hearing disorders. Most will have familiarity with peripheral hearing evaluations
		- Status: Consensus reached as written.
	+ Statement A2: Refer all patients ages 8 and above to an audiologist, with specific expertise in auditory processing, before surgery.
		- Discussion: Members agree that pre-operative referral is recommendedge. Age could be adjusted down to 7 years given normative data. Members agree that referral to a neuroaudiologist is best where possible. Age and cognitive status may be significant factors impacting the feasibility of this recommendation
		- Status: Consensus reached as written.
	+ Statement A3: Refer all patients ages 8 and above to an audiologist with specific expertise in auditory processing after surgery .
		- Discussion: Members agree that post-operative referral is recommended. Further discussion needed to come to a consensus on the exact timeframe and frequency with which patients should be evaluated. Age could be adjusted down to 7 years given normative data. Referral to a neuroaudiologist is best where possible. Age and cognitive status may be significant factors impacting the feasibility of this recommendation
		- Status: Consensus reached as written with **further discussion** on time frame and frequency with which patients should be evaluated.
	+ Statement A4: Patients should anticipate new onset auditory processing impairments following hemispheric surgery. The following skills may be impaired [table]
		- Discussion: Members agree that hemispheric surgery will have an impact on auditory processing. Group did not discuss or settle on an exact list of skills that may impacted at this meeting.
		- Status: Consensus reached as written. **Further discussion** on table elements required.
	+ Statement A5: Patients should anticipate worsening or, alternatively, improvement in pre-existing auditory processing impairments after surgery.
		- Discussion: Members pointed out that many patients may present at baseline with CAPD, which can complicate evaluation of changes, especially subjective evaluation. Lack of pre-operative testing complicates the matter of evaluating change in CAPD. Suggestion that patients may be used as their own baseline in longitudinal testing.
		- Status: **Requires further discussion.**
	+ Statement A6: Evaluate all patients routinely for central auditory processing disorders after hemispheric surgery.
		- Discussion: Members raised similar points in various statements above.
		- Status: Requires **further discussion.**
	+ Statement A7: [N/A - misnumbered]
	+ Statement A8: The following formal assessment tool/s should be used during evaluation and management of central auditory processing [table].
		- Discussion: Brief discussion about various evaluations. embers did not settle on an exact list of recommended evaluation tools or rehabilitation strategies at this meeting.
		- Status: Requires further discussion.
	+ Statement A9: The following patient-specific variables (e.g., etiology, age at surgery, duration of disease, hemisphere, etc.) appear to predict auditory outcomes following surgery [table].
		- Discussion: Members loosely discussed the impact of patient-specific variables on the feasibility of evaluation. No discussin discuss how patient-specific variables may impact or be associated with CAP functioning itself.
		- Status: **Requires further discussion.**
	+ Statement A10: Deficits in central auditory processing can have the following functional impacts:
		- Discussion: Members discussed some accommodations and strategies that may be useful, but no consensus was reacedh at this meeting.
		- Status: **Requires further discussion.**
	+ Table of Symptoms of CAPD
		- Discussion: Members did not discuss this point in depth during the first meeting. Members briefly discussed other auditory-related issues outside of traditional CAPD including hyperacusis. Status:
		- **Requires further discussion.**

Action Items:

* Summary and Input: M. Jones will prepare a summary of the discussion and poll for next meeting.
* Future Presentations: Plan to present findings and gather further feedback at the upcoming research meeting in Boston, August 1 (F. Musiek - virtual presentation).