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What's New?

Aligning Practice to Research (finally!) to Support Children with Microtia Atresia

EHDI 2022

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1

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Learning Outcomes

Participants will be able to…

01	02	03
describe gaps in research related to young children with microtia/atresia.	identify important findings from recent research.	apply findings from recent research to support children and families, the EHDI process and/or their own practices.

2

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Common Questions

What caused this? Are there other medical issues?	How will they do in school?
Does my child need a BCD?	Will my child get picked on or bullied?

3

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Risk factors and etiology

4

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Risk Factors

- Maternal risk factors for severe microtia/atresia in China: A case-control study. (Liu et al., 2018)
- Sociodemographic, health behavioral, and clinical risk factors for anotia/microtia in a population-based case-control study. (Ryan et al., 2019)
- Does Prematurity Play a Role in Newborn Microtia-Anotia? (Shehan et al., 2022)
- Maternal occupation as a nail technician or hairdresser during pregnancy and birth defects, National Birth Defects Prevention Study, 1997–2011.(Siegel et al., 2021)
- Population-based birth defects data in the United States, 2011–2015: A focus on eye and ear defects. (Stallings et al., 2018)

5

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Suggested Risk Factors

- History of miscarriage (5.5x higher with 3 or more), progesterone use, bleeding/cramping during pregnancy,
- Exposure to chemicals, such as pesticides, formaldehyde
- Prematurity
- Non-singleton birth
- One or both parents Hispanic, mother born outside the US
- Mother's binge drinking, drinking 300mg or more of caffeine daily, or smoking 5 or more cigarettes daily.
- Mother: Type 1 or Type 2 diabetes before pregnancy (Ryan et al., 2019)
- Anemia in first trimester

6

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Associated Medical and Health Needs

7

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Overall Associations

Congenital abnormalities associated with microtia: A 10-YEARS retrospective study. (Paul et al., 2021)

- Retrospective/observational study. (N=694)
  - Hemifacial microsomia 29% (45% of syndromes)
  - Inner ear malformations 10.9%,
  - Velopharyngeal insufficiency, Clefts 9%
  - Ophthalmological abnormalities 6.2%
  - Vertebral abnormalities 6% Cardiac 5% Kidney 3%.

Recommendation:

- Systematic analysis and screening for all associated abnormalities should be done for all children with microtia.

8

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Renal Screening

Renal anomalies and microtia: Determining the clinical utility of screening affected children. (Kini et al., 2020)

- Retrospective study of 98 children who had renal ultrasounds
  - Non-syndromic(n=84) Syndromic (n=14)
- 25% had structural abnormalities, 1/3 required follow up
  - 22% of non-syndromic 43% of syndromic

Renal ultrasound abnormalities in children with syndromic and non-syndromic microtia. (Koenig et al., 2018)

- Retrospective study of 80 children who had renal ultrasounds
  - Non-syndromic(n=29) Syndromic (n=51)
- 16% had structural abnormalities, 2/3 required follow up

Recommendation: Screening for all children with m/

9

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Heart

Congenital heart defects in patients with isolated microtia: evaluation using colour Doppler echocardiographic image

(Guo et al., 2021)

- N=804 isolated microtia/atresia (ages 1-31 yrs)
- CHD found (n=52), with 9 having 2+ CHD
  - Atrial septal defect, ventricular septal defect, patent ductus arteriosus
- No difference based on type of microtia/atresia
- CHD higher in m/a population than general population
- CHD might not be found at birth for isolated m/a

Recommendations:

- **Doppler echocardiogram at birth**
- **Screened prior to any surgery**

10

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Soft Palate and VPI

Soft Palate Dysfunction in Children With Microtia.

(van Hövell tot Westerflier et al., 2019)

Prospective study of 67 children with microtia atresia

Unilateral (n=40) results:

VPI-60% Uvular Deviation- 95%

Bilateral (n=27) results:

VPI- 85%

Uvular Deviation- 59%-almost no movement 40%-deviation

Recommendations:

- Children with isolated and non-isolated microtia should have in depth evaluation of soft palate movement and VPI

11

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Evidence Informed Considerations

- Children with microtia/atresia should be referred to a craniofacial team for a thorough, systematic analysis and screening for all associated abnormalities related to microtia should be considered.
- Children with non-syndromic or isolated microtia with CHD may have been missed at birth. They should be screened prior to any surgery.
- Detailed family and pregnancy history should be collected- information may help parents.
- **Children with isolated and non-isolated microtia need in depth evaluation of soft palate movement, hypernasality and VPI**

12

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IMPACT OF AURAL ATRESIA ON HEARING AND RECOMMENDATIONS ON BONE CONDUCTION DEVICES

13

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Clinical consensus document for fitting non-surgical transcutaneous bone conduction hearing devices to children. (Bagatto et al., 2021)

Pediatric Bone Conduction Working Group

Purpose: Address the assessment, selection, and fitting for non-surgical bone conduction devices for children under age 5

- Goal is to fit within 1 month of diagnosis
- Children as young as 2 months
- Bilateral m/a….bilateral BCDs (sequential, based on age)

14

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Poor speech recognition, sound localization and reorganization of brain activity in children with unilateral microtia-atresia. (Liu et al., 2021)

27 children with unilateral m/a, 27 matched controls

M/A children

- Poorer speech recognition and spatial listening
- No difference in cognitive scores
- Brain/neural activity via fMRI
  - Increase in visual networks
  - Decrease in auditory and attention networks

15

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Acquisition limitations of bone conduction hearing devices in children with unilateral microtia and atresia

Alexander, N. L., Silva, R. C., Barton, G., & Liu, Y.-C. C. (2020)

- 94 children-unilateral microtia/atresia, conductive HL
- 67 completed ABR testing & counseling on benefits of BCD
- 50 fit. Mean age: **20.8 months**/median age: **15.9 months**
- Barriers:
  - not showing for ABR
  - communication barriers
  - insurance coverage
  - parent concern about child use

16

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Are children with unilateral hearing loss more tired?

Carpenter, D., Dougherty, W., Sindhar, S., Friesen, T.-N., Lieu, J., & Kesser, B. W. (2022).

- Compare listening fatigue in UCHL, USNHL, LRNH
- (USNHL) (n=27) (UCHL) (n=42) (LRNH) no hearing loss

Child report:

Overall: UNSHL > UCHL, LRNH UCHL ≈ LRNH

Parent Report

Parents of UCHL reported higher levels of fatigue

17

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Bilateral Application of Bone-Conduction Devices

den Besten et al., 2020:

- Bilateral BCD fitting provides more support for sound lateralization and localization than one device, though lateralization is more likely than localization

Caspers et al., 2021:

- Experienced adult BCD users could lateralize sound and 1/3 localized sound accurately

18

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Evidence Informed Considerations

- Fit BCD within 1 month of diagnosis, age is not a barrier
- Fit 2 BCDs for bilateral m/a, sequential if needed
- Barriers need to be addressed:
  - Families from vulnerable backgrounds need more support to move from dx to fitting
  - Insurance/funding is a significant barrier
- CHL has less listening fatigue than SNHL. CHL may not be aware of their own listening needs.

19

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SOCIAL/EMOTIONAL DEVELOPMENT

20

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Behavioral Adjustment of Preschool Children With and Without Craniofacial Microsomia. (Johns et al., 2021)

- Overall, similar to children without CFM
- 20% children: may demonstrate "Internalizing Behaviors" (emotionally reactive, somatic complaints, anxiety/depression, withdrawn)
- Parent concerns about stress and anxiety , such as being too dependent
- Speech and peer relationship concerns could be misdiagnosed as ASD

RX: early screening/interventions, parent intervention models ASD caution

21

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Behavioral performance and self-report measures in children with unilateral hearing loss due to congenital aural atresia. (Cañete et al., 2021)

- Worse when noise is directed to good ear, speech to CAA
- Required higher SNR in the hearing ear
- Sound localization impaired
- Self-reported higher classroom difficulties-especially for listening in noise or listening activities. "Quiet" classrooms aren't quiet
- Parents and older children report difficulties in all areas of SSQ

RX: Preferential seating- not sufficient for classrooms

22

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Parental Reports of Intervention Services and Prevalence of Teasing in a Multinational Craniofacial Microsomia Pediatric Study. (Johns et al., 2021)

- 169 children, average 10 years old
- 40% parents reported their child being teased
  - 49% reported "some of the time"
  - 39% reported "almost never"
- Teasing started around age 5 (US), age 7 (South America)
- 85% teasing occurred at school
- No correlation with amplification, HL, IEP services
- Higher teasing for children with m/a and mandibular hypoplasia

23

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Exploring the Experiences of Adults With Microtia: A Qualitative Study. (Hamlet & Harcourt, 2020)

- Challenges/Anxiety-hiding ear, others finding out, disclosing
- Surgery as adult isn't a quick fix for anxiety, self-esteem issues
- Adults did not view microtia as a negative impact on life
- With age, insecurity lessens. Family/friends made a difference

Recommendations:

- Psychosocial supports for parents & young children considering reconstruction
- Assessment of patients/parents' expectations for reconstruction and realistic outcome counseling
- Psychosocial support/interventions related to visible differences

24

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Evidence Informed Considerations

- Early screening and interventions are needed to address anxiety, communication impacts on peer relationships, independence, visible differences, self-esteem for children and for parents
- Collaboration with ASD professionals for appropriate diagnosis
- Classrooms are never quiet, preferential seating is not enough
- Schools play a role in supporting children before teasing starts

25

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School Related Outcomes

26

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Hearing-related quality of life, developmental outcomes and performance in children and young adults with unilateral conductive hearing loss due to aural atresia. (Smit et al., 2021)

29 participants, ages 7-19 years, 3 age groups
-Standardized measures: quality of life, behavior, communication, overall development

- 44.8% report using amplification
- SSQ-quality of life lower than general population
- Social/Emotional, Behavior, Language-within average range
- 34% repeated a grade and 2 were in special ed. class

27

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Impact of unilateral congenital aural atresia on academic Performance: A systematic review.

(van Hövell tot Westerflier et al., 2018)

- Only two studies could be identified
  - High selection bias
  - No standardized outcome measures
- Other studies were excluded based on:
  - SNHL included or not specific if AA dx.
  - Type of article (ie narrative review)
  - Multiple studies using same participants
  - Missing full texts, unable to obtain

28

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Outcomes for School-Aged Children with Aural Atresia. (Hyland et al., 2020)

- 10 children with AA (8 UL) vs 10 control
- Language, reading, classroom, quality of life
- All had early amplification (5 current/7 FM) & LSL support

Results:

- 90% AA ≥average Vocabulary, Language and Reading
- 70% AA ≥average functional communication
- HEAR-QL-significant differences from control group
  - Experiences difficulties hearing in different situations
  - Frequency of HL having a negative impact on their feelings

29

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Evidence Informed Practices

- Provide early amplification and intervention to improve language and academic outcomes
- AS IF-quality of life impact needs support beyond amplification
- Psychosocial Development-development of healthy self-esteem and of communication strategies for social situations
- In absence of research-address amplification, intervention and academic support and psychosocial needs for positive outcomes

30

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Questions?

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31

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32

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33

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34

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35

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36

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37