CHILD AND PARENT PRIORITIES FOR MISOPHONIA ADVOCACY, TREATMENT, AND RESEARCH

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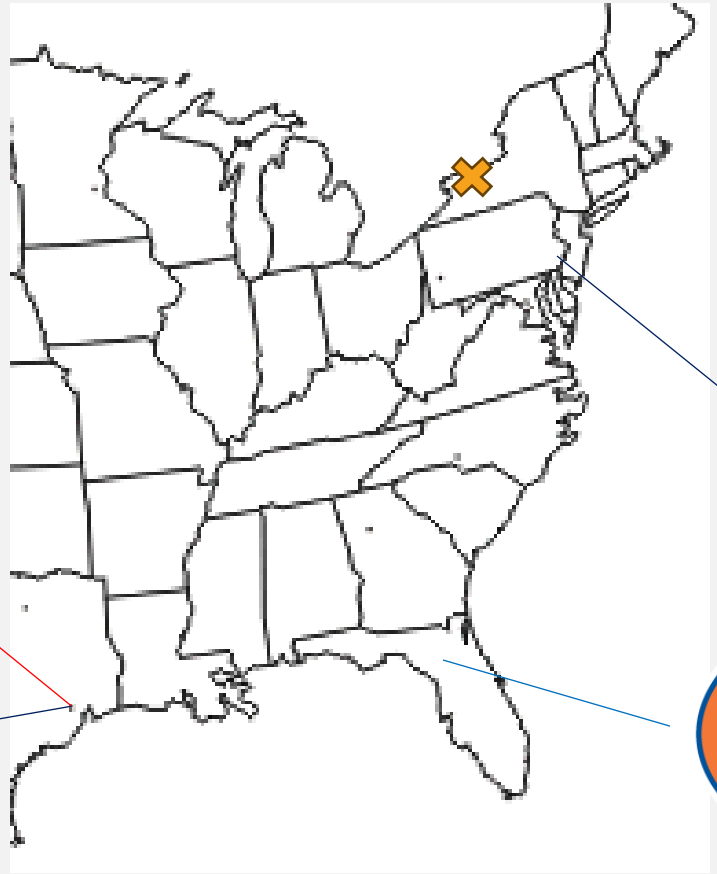
ABOUT ME



Texas Children's Hospital®

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WHERE WERE WE A FEW YEARS AGO WHEN WE STARTED THIS RESEARCH?

- Almost no research in youth
- New and growing advocacy voices online
- Few clinical specialists
- Emerging research in disciplinary silos

KEY QUESTION: WHAT MATTERS TO KIDS WITH MISOPHONIA AND THEIR PARENTS?

- What do they want researchers and scientists to study?
- What kinds of treatments are they looking for?
- What advocacy and policy efforts need to happen next?

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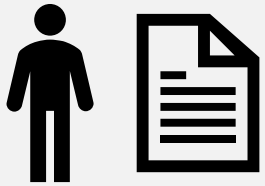
Advance breakthroughs. End suffering.

WHAT IS QUALITATIVE RESEARCH? IS IT EVEN SCIENCE IF THERE ARE NO NUMBERS?

QUALITATIVE THEMATIC ANALYSIS

Coder 1



"I really enjoy this presentation but the presenter is just a bit too boring for my taste. I'd prefer if he would have made a song about his research instead"

Coder 2

"I really enjoy this presentation but the presenter is just a bit too boring for my taste. I'd prefer if he would have made a song about his research instead"

Looking for 80%+ agreement across coders

Qualitative codes:

- Positive impression
- Negative impression
- Format
- Information/Learning

Braun & Clarke (2006). *Qualitative research in psychology.*

QUALITATIVE THEMATIC ANALYSIS

Look at all text with the same code

- I'd prefer if he would have made a song about his research instead
- I think interactive parts of the presentation would have been better
- He should have used examples I could understand

Themes = how we make sense of groups of codes

- "Lack of learner interest"

Discuss with research team and make improvements

- "Lack of learner interest" -> "Lack of learner engagement"

Share with participants for their feedback

- Did we capture your voice accurately?

Braun & Clarke (2006). *Qualitative research in psychology.*

MAJORS THEMES FROM INTERVIEWS

Themes were compiled based on interviews with 20 youth with misophonia ages 10-17 and their parents

Advocacy

- Advancing awareness for advocacy
- Misophonia is outside the child's control

Research

- Understanding the neurobiology of misophonia
- Defining misophonia beyond sound triggers (i.e., misokinesia)
- Understand the daily impact of misophonia
- What is the misophonia-mental health connection?
- Long-term prognosis

Clinical practice

- Practical and misophonia-specific therapies needed

Abraham et al. (2025). *Personalized Medicine in Psychiatry*

ADVOCACY

ADVANCING AWARENESS FOR ADVOCACY

I think there needs to be more awareness about it, so that people with misophonia can be open about it and explain it to people, and it's not like everyone gets all weirded out. So those people can feel comfortable being in public, [and] being like, "Hey, do you mind not eating in class. We're taking a test, I'm really trying to focus right now, this really bothers me." But, you know, I feel really reserved to say anything like that.

Abraham et al. (2025). *Personalized Medicine in Psychiatry*

MISOPHONIA IS OUTSIDE THE CHILD'S CONTROL

I would want people to know that it's an involuntary reaction… Because my mom has thought [that] she's having bad manners, or that I'm not disciplining her enough

Abraham et al. (2025). *Personalized Medicine in Psychiatry*

TREATMENTS

PRACTICAL AND MISOPHONIA-SPECIFIC THERAPIES NEEDED

- *It's currently being treated, in our case, as anxiety, and it's a very specific issue, that, I think, needs its own specific therapy*
- *I'd just like to see technology that really works, … you're not walking around with these giant headphones on. And something that's discreet.*

Abraham et al. (2025). *Personalized Medicine in Psychiatry*

RESEARCH

NEUROBIOLOGY OF MISOPHONIA

Seeing what happens in the brains when they hear these sounds and compare and contrast with other people who don't have [misophonia].

Abraham et al. (2025). *Personalized Medicine in Psychiatry*

DEFINING MISOPHONIA BEYOND SOUND TRIGGERS (IT'S NOT *JUST* A SOUND PROBLEM)

She can still hear the sounds through the floor and stuff. I'm like, is it a sensation, is it visual? Is it feeling? Is it a combination of feeling and hearing and seeing?

Abraham et al. (2025). *Personalized Medicine in Psychiatry*

INVESTIGATING THE DAILY IMPACT OF MISOPHONIA

- *Help the family too. So, focusing on that, I think we have to start with the person with it, but then eventually work with the family too because it's huge.*
- *Really understanding what misophonia is and what a severe impact it can have on the quality of life for someone is the most important thing.*

Abraham et al. (2025). *Personalized Medicine in Psychiatry*

THE MISOPHONIA-MENTAL HEALTH CONNECTION

I think they really need to be looking into the anxiety and the depression that also comes with this because you get in your own head, and you're like, "I'm so alone because no one understands what I'm going through."

Abraham et al. (2025). *Personalized Medicine in Psychiatry*

PROGNOSIS

Is this something that you can anticipate is going to get better with time, get worse with time? That data is something that if I knew as a parent, then I feel like I could help better prepare my child

Abraham et al. (2025). *Personalized Medicine in Psychiatry*

WHY WHAT WE LEARNED MATTERS

Publishing these priorities in scientific journals may give researchers ideas about how to make sure their research is as helpful as possible

Important ideas for advocates, healthcare professionsals, and researchers arose throughout the interview, many of which line up with the MRF, SoQuiet, and other players in this area

Show that there is so much room for improvement and that we need more progress

THANK YOU

- Katie Abraham
- Catie Rast
- Eric Storch, PhD
- Baylor College of Medicine
- University of Pennsylvania
- Misophonia Research Fund
- SoQuiet & Duke CMER