CIICA Conversation: Experiences of Tinnitus and Cochlear Implants

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Facilitators: Robert Mandara, Finland, Julianna Franchetti, UK, Kelly Assouly, Belgium

Observer, Sue Archbold, CIICA

Participants: 8 users of CI; 1 Researcher, 2 Advocacy leaders, 1 Teacher of the Deaf.
Live captioning was provided. CIICA Conversations last for one hour and are not recorded.
Participants were from 7 countries: Belgium, Finland, N Ireland, Netherlands, Slovenia, UK, USA.

Introductions:

Robert Mandara. Vice-President, EURO-CIU, Bilateral CI user & tinnitus sufferer
Julianna Franchetti, Bimodal HA & CI (2 years) , Tinnitus sufferer
Kelly Assouly, Researcher on the effect of CI on tinnitus - at UMC Utrecht (NL) and Cochlear (BE)
Attendees also introduced themselves via the chat room and beforehand.

Framing the Conversation

Robert introduced the possible issues to address, emphasising that we were discussing tinnitus AND CI
For example:

- Do cochlear implants make your tinnitus better or worse?
- Does mapping have an effect on tinnitus?
- In what situations is your tinnitus best and worst?
- How do you cope with tinnitus? What help do you need?
- Do your clinicians realize how bad your tinnitus is?

Summary of the verbatim live discussion, chat room comments, and those sent by email:

The impact of tinnitus:

The impact of tinnitus on lives was clearly huge and rarely understood by others, with little awareness.

"there wasn't much of an awareness out there that people with cochlear implant users or even with hearing people, they are not much aware about tinnitus."

Tinnitus was worst in:

- Quiet environment
- Loud environments
- When having hearing tested
- When the CI processor is not being worn

- When stressed
- When listening to music too loud or for a long time
- In long car ride

Various descriptions were used; for example:

- "Tinnitus is my friend: I am never alone"
- "It's my enemy that goes with me everywhere. I would be rid of it in a moment if I could."
- "I treat it like my own shadow, sort of"

Participants shared their experiences of the impact of tinnitus:

"I am partially retired because I have tinnitus."

"The worst time for me is night-time and when I am trying to get asleep- when it is very quiet. That is when I hear it the most and the hissing, screeching and wailing and a room full of people mumbling is hard to take. "

"I thought my grandson was crying and leapt out of bed and he was fast asleep. It was my tinnitus which was crying."

"I have had my tinnitus since I was 12 – it wasn't too bad because I always wore hearing aids – they masked the sounds. But when I suddenly lost my hearing I basically couldn't cope because the tinnitus was like I was somewhere near the aircraft- roaring engines. "

"We need to remember that the listening and concentration fatigue which affects us all but even more those with tinnitus."

Sleeping issues were common:

"Sometimes I think my tinnitus is so loud it wakes me up."

"I tried to wear my sound processor while sleeping,"

"what if we could wear our sound processor at night?"

There was discussion about how tinnitus can sound and the descriptions included:

- High pitch
- Crickets
- Clicking
- Baby screaming
- Aircraft noises
- Different forms
- Volume of a jet plane
- Tinnitus triggered when exposed to specific sounds, generally loud ones
- Slamming of a car door

Coping strategies

There were some common strategies to manage tinnitus including meditation and taking time out.

"I go to my favourite place and I pretend it's the sound of the sea and I am floating in the sea and can almost change it to the sound of the waves."

"I think if you dwell on tinnitus it controls you."

"I wish I had reached out to others early on but I was embarrassed"

"I sleep like a baby – because I am a workaholic. So I work myself so tired, that by the time I hit the bed, I'm out."

"I stay awake for as long as I can so I am super tired…"

"I try to be really tired, to fall asleep quickly without being annoyed by the tinnitus"

"*sometimes I imagine that the tinnitus is my mattress. Something that I am not afraid of or that's making me nervous. It generally does quieten the roaring or takes my mind off it."*

Impact of CI

Hearing aids did not seem to help tinnitus for the majority of CI users: CI could mask tinnitus and divert attention from tinnitus for some but not for all:

"it (CI) has helped me to cope with the tinnitus because without it I wasn't getting conversations .. so the cochlear implant has helped enormously with the tinnitus"

"I would say that my situation with tinnitus is much much better after implantation. It was terrible. I was so very down. When wearing hearing aids because it was so strong when they tested my hearing I was not able to recognise what was my sound and what was the external sound. After implantation, the situation is much, much better. …now I only have problems in the evening, it is difficult to sleep with noises in your head."

"I cannot say the implant took away the tinnitus – no – it's still there even right now."

"I feel like I need a break from my CIs by the end of the day, both physically and mentally. But when I take them off I am trapped with only my tinnitus. I identify with what J said about external sound being a distraction for our brains which allows me to focus on the constant shrill cacophony less."

"Since I had my CI I'm getting tinnitus more."

"I've had tinnitus since I was four. I was wrongly advised that cochlear implants might help my tinnitus. At best it has only changed the tinnitus. That's not to say I regret having implants, they are the best things I have done, but all the same tinnitus is the one thing that's not fixed."

"But since I've had my cochlear implant, I'm getting tinnitus more ……. I get butterfly sensation, my ear drum seems to be fluttering."

There was a discussion about the need for cautious advice about CI and tinnitus and the need to manage expectations.

Experiences in the clinic: Do your clinicians realize how bad your tinnitus is?

No one had experienced being asked about their tinnitus in the audiology or CI clinic.

“I had to be assertive and tell the audiologist that I had tinnitus.”

“*Audiologists need to ask and talk about it.”*

“I do not recall an audiologist asking me if I have tinnitus on the day I visit the clinic.”

“Never been asked- always had to be my own initiative but still not taken up afterwards.”

“I have brought it up with my doctor and the only response I have received is “to try and ignore it” – this was not a very compassionate response and quite depressing. I don’t feel like my doctors understand what tinnitus is like. “

All felt that it impacted on the effectiveness of mapping and hearing testing sessions:

“*Do we hear the sounds in our headphones or the sounds in our heads?”*

“The tinnitus can affect the mapping decisions for me in the way that the thresholds from the booth can be false. … because I struggle to check what is a real sound.”

“Booth sessions were really confusing and frustrating. What is a beep at 100dB+ and what is just my tinnitus? Beats me.” “I have had to bring up my tinnitus every time I see the audiologist. I feel it does affect my mapping. When I am trying to set thresholds, sometimes those beeps just get lost in all the noise in my head and I think it can vary from day to day.”

“When I get a new map, for a few days or weeks afterwards the tinnitus sometimes goes quieter. Then it comes back..”

There was felt to be no awareness and counselling about tinnitus by clinicians and little awareness by audiologists of its impact in the clinic in mapping sessions or whether there was the possibility of mapping which would help to manage tinnitus.

Tinnitus measurement

The discussion about tinnitus measurement emerged because of the wish to show others (partners, colleagues) the impact of tinnitus, and also to obtain an objective measurement of change in tinnitus.

Two examples were given where there had been attempts to simulate the tinnitus sound and this had been found helpful to share the problem and gain some understanding from others. For one, who had had the opportunity to develop a trial simulation of her tinnitus:

“*I played it to my partner and he said what the heck – you can’t be listening to that…. I don't know how you cope with it. I couldn't cope with it.”*

“It would be wonderful to have some way to compare and share. And for people who don't experience it to know what it is really like because it is quite difficult to carry around with us through our whole life…”

Tinnitus in children

The issue of tinnitus in children came up through the recollections of several users of having tinnitus as a child (without realising what it was)

“I had tinnitus since I was 4 but I did not know it was tinnitus. I didn’t tell anyone – I thought I was going mad.”

“I am suffering from tinnitus since I can remember. But at first, when I was a child nobody took that seriously.“

“I also didn't tell people until I read about the thing when I was older/ heard about other people with tinnitus. I didn't know its name originally, so... but somehow I generally knew what I was hearing in deaf mode wasn't real.”

“And I take on board to see that child again and sometimes they can't always explain what tinnitus is. So I get them to draw a picture and that's one step for us.”

“I had tinnitus from the age of 12.”

“we do not ask children the they have tinnitus or not because we are also afraid that we will maybe cause something, cause a burden for these children.”

The teacher of the deaf present also considered the children with CI she was working with: *“do they suffer from tinnitus? What questions should we be asking them?”* Further discussion took place about current work in the UK about paediatric guidelines - to be followed up.

Summary

Tinnitus is clearly a larger problem amongst CI users than currently realised.

- Need to raise awareness
- Need for awareness in clinics about its impact on audiology/mapping sessions
- Need for realistic counselling of expectations in CI
- Consideration of the impact of tinnitus for children
- Need to develop objective assessments, for example, to track whether treatments for tinnitus are truly effective.