

CIICA Conversation: Experiences of Tinnitus and Cochlear Implants

One person's hiss is another person's sizzle

11 October 2023

Facilitators: Robert Mandara, Finland, Kelly Assouly, Belgium

Observer: Sue Archbold, CIICA

Participants: 7 users of CI; 1 Researcher, 1 Audiologist, 1 Rehabilitation specialist, 2 Advocacy leaders,

Live captioning was provided. CIICA Conversations last for one hour and are not recorded.

Participants were from 10 countries: Australia, Belgium, Canada, Czech Republic, Finland, Germany, Ireland, Slovenia, UK, and USA.

Introductions:

Robert Mandara, Vice-President, EURO-CIU, Bilateral CI user and 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.

We named this conversation one person's 'hiss' is another person's 'sizzle' because when you try to describe what your tinnitus sounds like, people will use different words, If you ask people in the south of France what their tinnitus sounds like, they might say well it sounds like crickets, and in the north of France people would not use that same term at all, it depends very much where you go and what vocabulary you use to describe it.

Robert then introduced these questions:

- **How much you are affected by your tinnitus?**
- **In what situations does tinnitus disturb you most?**
- **Do your friends and family understand how tinnitus impacts on you?**
- **How do you describe it to them?**
- **What does tinnitus actually prevent you from doing (totally or partially)?**

Summary of the verbatim live discussion and chat room comments:

An audiologist kicked off with why it is important to give time to discussing tinnitus:

My predominant impression in working with CI users with troublesome tinnitus is they are more dismissed than other people with tinnitus, because they seem ungrateful. Somehow, to the medical

community or to the audiologists because they obviously have very big benefit for the most part from the cochlear implant and when they come back and talk about this really troublesome difficult thing that is really secondary in everyone's mind that they are not connected to it and they are dismissed and that carries a very big burden.

The conversation then went on to consider how tinnitus affects people in different ways.

(Before CI) my tinnitus was reactive to the sound environment I was in, the louder the sound environment the worse the tinnitus got, I stopped listening to music and podcasts.

After CI it comes back without my processor

I get tinnitus personally, I have bilateral cochlear implants and I get tinnitus a lot of the time. I run, so, sometimes after I finish a long run I get it quite a lot then. Also when something really bad has just happened, when I have not got my ears in as well, my cochlear implants.

The conversation went on to discuss how to talk with families about tinnitus and the impact on the family too:

My family had a good understanding of it; I am looking at your list of questions. But you know they forget about it. It's obviously not on their mind because they are not in that situation,

(Before CI) the kitchen in the home was difficult, I have young kids, so, you know the tinnitus got louder and louder based on whatever sound environment you were in.

(Before CI) I can say my hearing had been worse with tinnitus and it was really, really hard to live with such a different sound in your head. I don't know now how I survived, how I worked in that time. How I take care of my children and I really don't know how I was able to survive, so, loud tinnitus in my head. Especially if I was in a noisy environment, the situation was very much harder than if I was in a quiet environment, but I worked in quite a noisy environment.

(Before CI) a year on, you know socially, personally, occupationally, it affects everything, you know, it's very pervasive it can be isolating. It can isolate you at work or could isolate you domestically, you know people don't want to be around loud noises in the kitchen, if your children are screaming you are physically isolating yourself. You don't want to go in one of the worse social situations you go into a reverberant room there is a round table and you are expected to talk to people in that setting and your tinnitus will get set off by that, you know, it is, I think has a massive effect on quality of life, severe forms of tinnitus.

I had broadband tinnitus, it affected multiple frequencies and it could get quite loud and affect my ability to concentrate you know. Fine you get through the working day but you go home afterwards and fall asleep straight away because of fatigue. The impact is profound.

One person with Single Sided Deafness talked about the change after CI:

I am talking in retrospect here because my CI has been effective for my tinnitus, if I go pre-implantation how much I was affected by my tinnitus, it was quite severe and affected me from a listening fatigue perspective, it affected me at work, my ability to concentrate and find words and you know I could see it, I could hear it in my speech

Managing tinnitus:

I may put it low volume masking sound when reading a book for 20 minutes that is the extent my tinnitus will affect me, most of the time I can't hear it

Kelly asked whether people avoided noisy environments:

I don't avoid the noisy environments. When I am in the noisy environments like when we were in Rotterdam a few months back, a very noisy environment, but I could hear well in that environment, it was not bothering me there. But when I got back to bed that evening my head was screaming. In the moment it was okay but at the end it started, but I don't avoid noisy environments.

(Before CI) I did avoid noisy situations before the CI. But then I gradually exposed myself to them more and more so I did not get isolated and I wanted to get desensitised and get habituation stage.

I work before in a noisy environment, that was very stressful, but after 7 years I changed position and I am now in a more quiet environment. It is much, much better.

Tinnitus affects audiology assessments:

When I had audiograms I was not able to recognise what is the sound from audiogram you know that beep, beep, beep and what is my tinnitus so I usually say I don't know what I hear. I am not sure. Is that you or me, I don't know.

I had tinnitus in my right ear but I had the cochlear implant in my left ear. I didn't notice any change in my tinnitus. I know when I am not wearing my hearing aid in the right ear that my tinnitus is more pronounced and I know that if I am very tired I am, you know, aware of the tinnitus, but I am never really bothered by it, I kind of sort of try to think, what frequencies, what does it sound like and as an audiologist as well, I kind of correlate my tinnitus as to where my hearing levels at a threshold.

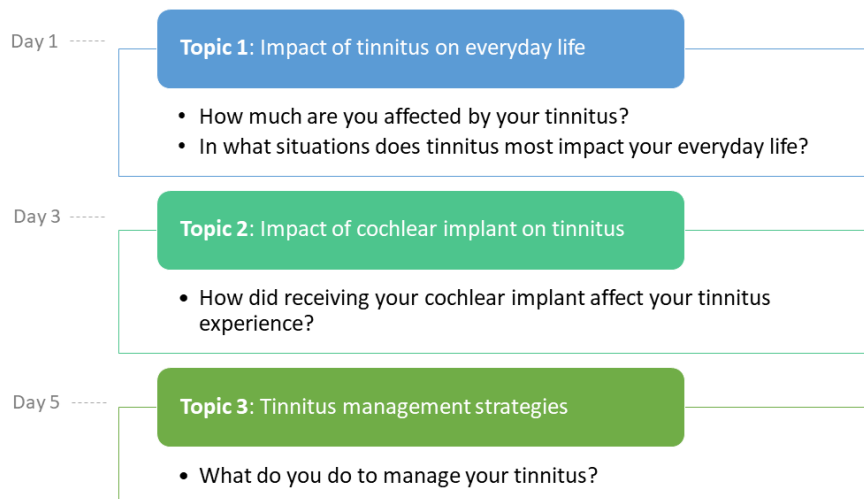
Kelly Assouly shared her research about tinnitus which looked at the impact of tinnitus on CI users older than 18 years, in 6 countries. Her PP is attached as a PDF. She used a mixed -method approach with an online forum discussion first, followed by thematic analysis of the conversations, then the development of a survey which went out more widely. Here are the questions that she used:

PLOS ONE

RESEARCH ARTICLE

The impact of tinnitus on adult cochlear implant recipients: A mixed-method approach

Kelly K. S. Assouly^{1,2,3*}, Maryam Shabbir⁴, Bas van Dijk³, Derek J. Hoare^{4,5}, Michael A. Akeroyd^{4,5}, Robert J. Stokroos^{1,2}, Inge Stegeman^{1,2}, Adriana L. Smit^{1,2}



Forum findings

136 people participated in the forums: these were the findings:

- Tinnitus experience can depend on the sound processor usage.
- Difficulties vary among CI recipients.
- Tinnitus management can differ between day and night.

Survey findings:

414 people responded to the survey:

- Tinnitus seemed to increase when performing a hearing test or CI programming session, when being tired, stressed or sick.
- Difficulties are more frequent without sound processor.
- Fatigue, stress, concentration, hearing difficulties were the difficulties more reported.
- To manage their tinnitus, recipients reported turning on their sound processor and avoiding noisy environments.

Tinnitus impact can depend on the sound processor usage:

- 63% rated tinnitus as a small problem to not a problem with sound processor.
- 70% rated tinnitus as a moderate to very big problem without sound processor.

Summary:

- Tinnitus experience vary among people.
- Tinnitus presence and impact depend on the sound processor usage.
- Healthcare professionals should be aware of the impact of tinnitus on CI recipients.



Tinnitus experiences vary among people.



Tinnitus presence and impact depend on the sound processor usage.



Healthcare professionals should be aware of the impact of tinnitus on CI recipients.

There followed useful discussion about the findings of the research:

My question for Kelly and it came up in the initiative conference as well, sub typing of tinnitus, where are we on that, because I felt that when some people were discussing tinnitus they were given advice that did not apply to me, I could not mask it because I had no hearing to hear the masking.

Loud environments made it way worse. It was like it added to it and I got successively worse as the day went on. I think there are different sub types of tinnitus. I don't think we can type them accurately yet, maybe there is that separation why one third of the population has a good response. If we can expand that so people are helped from a tinnitus perspective or how people respond to their CIs it would be great for a research perspective .

It different for people that suddenly lose their hearing to people who are born with a degree of hearing loss or graduate their hearing, so again the sub types are really important because the impact could be orders of magnitude away depending on the type of tinnitus you have.

From Kelly:

We cannot sub type because we do not have enough data. We are trying to collect a lot of data to make sure we can then see if we have sub types by having a lot of people profile but currently that is also a real limitation because we put everyone in the same group and it's not the same outcome at the end and that maybe why, depending on your hearing loss, also the cause of your tinnitus and your hearing history might also have different effects. I hope to give some answers in the coming months if we collect more data on this topic, but it's a good idea to work on sub type.

From another audiologist:

Our limitation with tinnitus more generally rather than just in the CI world is absolutely about sub typing. If we look at the studies they are really poor specifically selecting the client group or tinnitus type to treat. Therefore we look at the overall effect and say that this did not work and that did not really, but the name of the game is to understand the sub types that means physiological sub types and treat those specifically but we are woefully poor at that understanding. So what the tinnitus research initiative is doing is trying to gather world data from clinicians from myself, like Kelly, where people input all sorts of stories and then using AI and similar approaches we actually try to tease apart different presentations and see if we can understand, bit by bit, the causal mechanisms and treat those specifically. At the moment, we are dishing out the same treatment without knowing the cause.

From a CI user:

When you speak to a doctor that you have tinnitus. They never ask what sort of tinnitus, what does it sound like, personally, I feel quite strongly that different sounds are probably associated with different causes. But until anybody is asking then we are not going to know the answers.

But we can say that I don't know, for the last 3 years we speak more about tinnitus and more people speak about tinnitus and it is recognised in fact, like a problem.

But talking more about it can be a problem too:

I agree there is a lot of people who do something to just not think about it, but when you speak about tinnitus it becomes harder because you speak about it and then you think about it and then it's harder to deal with it. I agree with that we should distract from it but also we make sure we can discuss it when we want to share what we think about it.

Kelly's summary:

So, I think the main thing is that we always discuss what is the effect of cochlear implant on tinnitus to first understand what is a change and how you deal with this change. It has been reported that tinnitus was worse before cochlear implant, and that it's also because you cannot hear and so tinnitus is something on the top so you were also in a stressful environment and that is also harder to cope with tinnitus also when you cannot hear what is around you.

It also has been said that tinnitus volume changes after cochlear implant, for some people, and that's if tinnitus is in the other side and that you have the cochlear implant not in the side of your tinnitus, then it's, it cannot change so that is something which is also interesting for me as a researcher to know that maybe the side is doing something. We also know that sometimes cochlear implant on the one side can help the tinnitus in the other side thanks to something that is happening in your brain. There is still something to understand more how one thing in one side can impact the other side or not.

Then we also discussed the impact of tinnitus, so, there were a lot of things. It has an impact socially, also at work, you tend to isolate yourself, physically but also socially it has a real impact of quality of life and also emotion, how you deal with this, so also something, we know, but it might depend on the situation and from people to people but it's really important I think to make sure that people understand what is the impact of tinnitus to make sure that you can be also helped and have support when it's too hard to cope with it.

Then the situations there were a lot of different things. So, I heard that when there are noisy environments, before having cochlear implant for instance tinnitus tends to become louder, but it seems that noise can be something positive to make sure something is around so you don't hear it. It's also interesting to see there is a positive and negative side of being in a noisy environment. It was also stated in the evening when you are not wearing the sound processor, when you are tired, tinnitus seems to be labour some, doing hearing tests, running or doing physical exercise, when not wearing the sound processor or when something bad happens the tinnitus is something, on the top of all of this it is pretty hard to deal with.

It was interesting to hear at the beginning that people having tinnitus sometimes are dismissed by clinicians because, there is no solution for tinnitus so it's pretty hard to take it seriously, I hope this way of thinking will change and that people can also just discuss it. It's also important to make sure that people recognise that tinnitus is something and you are able to discuss it.

And we also discussed new ideas, so this sub typing is something I hope we will also be able to work on in research and also this idea of the duration of tinnitus which might influence how you deal with it, and there is also no research about that so it might be something interesting to discuss.

Last comment:

Possibly the last great problem in hearing care: We can give people that can't hear hearing, but we still can't solve the tinnitus

Thanks to all who joined us and Kelly and Robert.

Sue Archbold, October 2023.

Brian Cleary fascinating blog: <https://noisysilence.ie/>