

CIICA Conversation: ADULTS WITH CI: Impact on the family

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Žana van de Langkruis, Psychologist, daughter of Darja, Netherlands

21 Attendees from 8 countries: 10 users of CI; 2 audiologists (2 of whom also CI users), ENT, family members, industry. Live captioning was provided. Participants were from Belgium, Canada, Finland, Netherlands, Serbia, Slovenia, UK and USA.

Introductions:

Kris welcomed everyone, provided some Housekeeping notes and encouraged attendees to also introduce themselves via the chat room. The Conversation began with Nikki Philpott presenting her research, Towards personalised adult CI services, followed by Robert's discussion of the impact HL and CI had made on his family life, with his wife, and then by Darja and Zana sharing the impact of HL and CI in an adult on her children. We have only done light editing for this conversation and leave much of the contributions in full to give the depth of the discussion.

Kris introduced Nikki Philpott, who presented her recent research.



Towards personalized adult CI services:
The importance of communication partner involvement

Nikki Philpott, Hugo Nijmeijer, Birgit Philips, Emmanuel Mylanus & Wendy Huinck

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NIKKI: *I am talking about some research we did as part of my PhD at Radboud University Medical Centre in the Netherlands. I work there as an audiologist and as a post-doctoral researcher and what we did in the study is we wanted to look at the impact of a cochlear implant not just on the individual receiving the implant but on the communication partner who was walking that journey with him.*



We know that neither hearing loss nor coping with hearing loss happens in isolation. There can also be a mismatch and expectation on both sides: the CI user and also the partner. We know that a cochlear implant isn't a plug-and-play device. It's a lot of long work both for the user but also for the person walking that journey with them. The question that we asked was: How does hearing loss impact the quality of life for the CI user, and also for the communication partner who's walking this journey with the CI user?

Our methods: *We provided questionnaires to both CI users and also their romantic communication partners in this case, both before the individual received an implant and then again one year after. The questionnaire specifically related to quality of life, of both the user and their partner, specifically related to hearing or hearing loss. We then also compared how these quality of life ratings correlated with the CI user's speech perception: did a high speech perception mean that both a CI user and their communication partner both had a high quality of life compared to before implantation? We know from previous research that better speech perception doesn't always mean that you have a better quality of life, and that's often because the way that we measure speech perception in the clinic is in a perfect environment. CI users here will know this. It's measured in a sound proof booth, often with individual words or sentences in quiet. Daily life isn't quiet, so it's unsurprising that speech perception isn't always correlated well with a CI user's quality of life. Importantly, what we also saw is **it also doesn't correlate with higher partner quality of life.***

Our Findings:

- Speech perception in quiet has no correlation with a better quality of life in communication partners
- Higher user speech perception \neq Higher CI user quality of life **NOR** higher partner quality of life

For example, a CI user scoring 85% speech perception after one year with an implant doesn't necessarily mean that the partner suddenly has a higher quality of life related to the CI user's hearing.

We also learned that partners shared the lived experience challenges experienced by CI users, so when a CI user had a low quality of life, especially in domains like entertainment, social interaction and challenging listening environments, their partner also experienced a low quality of life in those scenarios. This was really interesting because it means that communication partners can actually be really valuable during a consult; they can often bring extra information, a different perspective, their own lived experience in this journey, and it really helps create a more holistic way that we can better support both users and their partners in this journey.

I am really curious to learn from people who are in this call today: what did your partner or families' involvement look like in your CI journey, and were they involved in conversations? Did the audiologist or the speech therapist bring them in? Did they make them part of your journey? Did they also receive support? I would love to hear from anyone in the chat who's willing to share what that looked like for them or if there are any partners here, I would love to hear from you, too.

Kris asked if there are any surprises with this result.

NIKKI: *I think we would have predicted the lack of correlation between speech perception and CI users and their quality of life. But specifically looking at communication partners, that's an area that's really not focused on a lot in research, and specifically in our case it was romantic communication partners and that was surprising to me, that was really interesting.*

(Citation: Philpott, N., Nijmeijer, H. G. B., et al. (2025). Beyond hearing: the impact of Cochlear implantation on the quality of life of users and their communication partners after 1 year. *International Journal of Audiology*, 1–7. <https://www.tandfonline.com/doi/epdf/10.1080/14992027.2024.2441332?needAccess=true>)

Kris then shared comments sent from South Africa by Jacqueline Barnardt about her husband's CI:

I loved dancing, but since you got the CI you seem less confident about hearing the beat of the music and avoid spontaneous dancing.

The mini mic is hugely supportive in conversations while traveling together as it minimizes the need for lip reading and turning attention away from the road.

Did families join in the CI journey?

DARJA: *My whole family was involved in the process with me which I think was very helpful. I have two adult children, each of them came to several appointments and my husband came as well. I think it really helped because they understood what the expectations were for my speech perception in the end. But also had a much more realistic expectation once I had my surgery, so I think that was very positive for everyone. I can honestly say everyone in my family would say there has been an incredibly positive impact on our family since I got my implant, specifically because I can now hear on the phone which is something I haven't been able to do since 2005, and so it has made a huge difference for my husband who has health issues, my two adult children and also my grandkids who I can now hear on the phone.*

Unrealistic expectations and adjusting to new hearing

ZANA: *I know when my mum got the cochlear implants, I was still in my teenage years - I remember her explaining to us how she's going to get this cochlear implant and in Slovenia you say it's like a kind of a snail thing, so I really thought she's getting a snail in her head that's going to help her hear and I did think that she's just going to get it in and boom! She can hear! So for me seeing how much my mum still learns and having to re-learn how to listen was very impressive and I remember she would ask us to do different sounds in front of her. So she would try to remember how she used to hear it and how she hears it now and as she was describing sounds like Oh, it's more metallic than it used to be and changing the settings. I didn't know that the process is going to be half a year, a year long. I thought she's just going to get this snail in her head and she's just going to hear. But yes, so I guess that was a bit unrealistic from my side. But, yeah, it was very impressive to see how just re-learning to listen works.*

NIKKI: And it's just this expectation that the activation of the implant is like putting on a pair of glasses for the first time and that everything is just immediately clear. Oh, it actually wasn't what I was expecting. But then once they have adjusted those expectations, you actually really see how well partners can be supportive in the weeks and the months that follow and how they can so clearly notice the improvements and it is small things, like Žana said. Partners will say: I didn't know you couldn't hear the kettle, or the clock in the lounge. I just had not even noticed the sounds any more. So you get to see this joy of re-appreciating sound not just from the perspective of the CI user but also from the perspective of their partner.

ŽANA: That reminds me when my mum was complaining she hasn't heard crickets in 20 years and one time we were walking outside and she's, like, what is this annoying sound that I keep hearing? Mum, those are crickets! And I was thinking how annoying crickets can be but to my mum that moment was like just such a special moment. Hearing crickets again....

ROBERT: With a cochlear implant you're not just learning to hear, but you're also learning not to hear. For example, I didn't know that the fridge made a noise. It makes a constant noise but I never knew this. You can either choose to let it irritate you or you acclimatise to it and ignore it. But there are a lot of sounds that hearing people pay no attention to, which bother us on the journey. I had to ask my wife many times "what's that noise? What is it I can hear?" Without any idea of where it was coming from or what it was.

Robert described his experience with deteriorating hearing before CI:

- I was withdrawn, frustrated, volatile and dependent on others.
- My wife was my secretary and interpreter => emasculating.
- I felt like an extrovert straitjacketed into introversion.
- Problems in work, study and social life were all brought home to the family. My sons were teenagers then.
- After so many years, my wife didn't dare hope for much from CI.
- CI as a subject impacted on the family long before I got one... wasted years of denial, deliberation, rejection and indecision.
- Initially, post implantation, my wife had to patiently endure "what can I hear?" a million times.

He went on to describe the positive impact on the family:

- We can converse room to room and even across our garden –being able to call "Dinner's ready!" matters.
- Independence: I can take care of my own phone calls / video calls – my wife is not my constant secretary or interpreter.
- Being far less angry makes for marital bliss (raising children would have been much easier if I'd had CI much earlier).
- We can enjoy live music, theatre, cinema etc. **together.**

Some positives are still waiting to reach full potential:

- We can converse in car but don't tend to do so.
- Family still hesitates to call me on the phone.

I interviewed my wife and came up with these topics, and I think it's important that we know where we started from before I got cochlear implants. I was born deaf and I've worn hearing aids since I was

four years old, so I was extremely withdrawn, frustrated and extremely volatile and angry and very dependent on others to help me. My wife was not just my wife, but she was also my secretary and interpreter, which was absolutely emasculating for me. I want to be able to look after myself. I felt like an extrovert trapped and strait-jacketed into an introvert persona. Naturally I had problems in my working life, studying life and social life and all of those problems were brought home to the family. My sons were teenagers at that time but, you know, in public you have to put on a civilised face; in the home you bring your anger home.

So, after so many years of being deaf, my wife didn't dare hope that much from a cochlear implant. She had obviously met people with cochlear implants but still there is range of outcomes, and you don't know where we are going to get to. In this conversation we are thinking about the impact of cochlear implants from the moment that you got the implants, but actually I would say the impact starts a lot earlier. I know someone here, before the meeting started, said that they had been waiting something like 17 years between applying for and eventually getting an implant. In my case it was the other way around. I was being offered an implant I think 18 years before I finally agreed to get one. All that time is spent on deliberating, rejecting, following media that's misleading and so on. It's all part of the journey which has an impact and I spent most of that 18 years saying: "Never, I am never getting an implant". Look at me now....

So, as I said a few minutes ago, initially post-implantation my wife had to patiently endure me saying, "What is that I can hear?" a million times. She was very patient.

There are two sides to this. There are positive benefits and also some negatives which I think are worth considering. I have bilateral implants and I've had them for 12 and 10 years I think. Now we can communicate from one room to another. Bear in mind that before getting implants I couldn't have a conversation sitting side by side with someone on my sofa, so communicating from another room is a big deal, but I can also communicate right across our garden which is, I don't know, 40 or 50 metres, I find it quite easy. So even a simple thing like, you know, being able to say, "Dinner is ready" from the kitchen and me being able to hear it takes a lot of weight off my mind. My wife doesn't need to come and get me and so on. I am independent now. I can take care of all my own phone calls, my video calls like this, so my wife is relieved of the secretary and interpreter duties.

I am far less angry than I was. I am still not a happy person. I worry a lot, but I am far less angry, it makes marriage a lot happier. I am kind of sad that I didn't get the implants a lot earlier, because raising children would have been much easier if I had had the cochlear implants earlier.

Nowadays we can enjoy live music, theatre, cinema together, and that's the word, "Together", because in the past my wife was going to these things on her own or with a friend because I couldn't get anything out of it. Some of these positives are still waiting to reach their full potential. For example, we can converse in the car now but we don't tend to do so, and I know the reason for this is that we have been married for 30 years, so, you know, she's had a long time with knowing that we can't communicate in the car. Usually we ended up in a shouting match of "Left! Right! Straight on!", whatever, and so it's tended to be silent and it's a habit now that, you know, my wife still doesn't talk to me in the car. I notice it if a stranger gets in that is new in my life because they will be yapping away... but likewise, you know, the family will still hesitate to call me on the phone, just because that's how it's always been. There's kind of no reason to change. But these are the things to get better.

Followed by the negative impacts:

- Without CI I am totally deaf now:

- My wife can't bang on toilet door in an emergency to get my attention.
- Pillow talk SHOUT is no longer possible.
- I'm less tolerant of ambient music in the house.
- Now I can, I want to dance, play sports, engage with people. Meanwhile, why should my wife want increased social contact?
- Time that I spent moaning about deafness has been replaced by time moaning about CI advocacy matters.

If we just think about a few of the negatives, they are not nearly as strong as the positives, but I do want to cover them. In the past I was able to hear if someone shouted in my ear or banged on a door; I could hear someone trying to get my attention. Nowadays if I am locked in a toilet or a bathroom, for example, my wife cannot bang on the door if a fire breaks out. We've never been able to have pillow talk. We could have pillow SHOUT, but even that's no longer possible. I cannot hear anything in bed, so, you know, it's either turn on the light or forget it.

Interestingly, music sounds different through implants, and I used to like music on in the background all day, just ambient music. Nowadays I am not so tolerant. I find it irritating, I can't quite work out what I am listening to a lot of the time.

Now that I can, I want to be able to go dancing, play sports and engage with people; my life has changed. But meanwhile, why should my wife have any reason to want more social contact than she has had in the past 30 years? It's my life that has changed, not hers. So, for every couple there must be variables that change that should be considered.

I spent most of my life complaining and moaning about deafness, but when I got implants, I never expected to be spending my life in meetings like this, advocating for cochlear implants. I was formerly President of EURO-CIU and involved in the local Finnish Association and it can be very irritating, very draining. I feel that pretty much all cochlear implant users are expected at some level to be ambassadors, advocates, marketing tools, for cochlear implants, but it's not something any of us expected to do before we got implants; someone should warn us.

The final slide I will leave you with a quote just from my wife, "Your hearing matches your personality now better than it did". As I say, I felt like an extrovert trapped in an introvert body and now I have the freedom to be myself. I am still not a wild person but I feel much more comfortable in my own skin.

Suzanne (attendee): I have been volunteering as an advocate since I first got my implant. For me it was something I was expecting and I was looking forward to doing. I have always worked in the disability awareness field so I co-ordinated support services to students with disabilities in a post-secondary institution. So I am happy to be advocating for cochlear implants. One of the things that I found to be an issue is the competitiveness between the cochlear implants companies, and I would like to advocate for people to help people make their own decisions, I am mentoring people who have implants from different manufacturers and I would like to see more of that because in, at least where I am living, we are finding many of the meetings are very focused on one provider, not on what it actually can be like for the individual who will be getting the implants, how we can help that individual with their decision, with their rehab, with re-integrating into their family and their community once they get the implant.

But I have had some strange experiences since I got my implant; I have actually been in social settings where someone has grabbed me and pulled me aside because they want to know about implants, and at first that was very startling to actually be grabbed by a stranger and pulled away

from the conversation, but I think that reflects how desperate some people are to know more about implants and how important it is to talk to someone who actually has one, so not just a service provider or a manufacturer but a person who's actually gone through it.

The assessment process and role of the family

In the area that we live in, the application process is quite rigorous and one of the steps is actually meeting with the social worker to determine if you have realistic expectations, but also the family support that you need with your recovery and your rehab, and I am fortunate I have a daughter who works in the hearing field; she's also someone who experiences a hearing loss herself. She went through a lot of the technical appointments with me and then afterwards was able to explain to me what had happened and what people had said because I went through the entire meeting not being able to follow the conversation at all.

I also received a lot of phone calls from health care professionals about appointments, about booking appointments, and finally my husband got frustrated and said: "Do you know why she's having this done?" And they said, "Yes, she's getting a cochlear implant". And so he said, "So why are you trying to talk to her on the phone?" And so that was really frustrating, because they were phoning my husband who would sometimes remember to tell me what the conversation was about and what the appointment was, but no one in the health care profession made an effort to text or email me.

And that made the process something I couldn't navigate with my hearing loss unless I had support. So, part of the reason I have so much support is I really needed it. I did give that information to the assessment people and to the health care service providers and they pretty much indicated that this was a confidentiality issue and that they couldn't text me, so at that time I could only respond to texts or email. They were also reluctant to put anything in emails. My husband pointed out that if my daughter answered the phone they would have no idea they were not talking to me. So this idea that if you spoke to someone on the phone it was somehow verification of their identity really didn't make a lot of sense, but that's what they stuck with. So the entire process was via telephone. I had my implant two years and half years ago.

Comment from another attendee: *I'm interested in how we can add more "conversation starters" into the CI journey. The first year of having a CI is a great time for families to have a kind of "communication reset." It's a chance to let go of coping habits that no longer help. If we don't prompt the right conversations, we can miss this golden opportunity.*

I would love to see a set of conversation prompt cards designed for families who are entering into the CI journey together. I would also like to see more resources made for people with hearing loss to share directly with the people that want to support them. This can also be a nice way to prompt conversations.

SONJA: I am from Serbia and I am CI user. Just yesterday was my birthday and, all my family were very scared about all that story of cochlear implantation but now they invite me with my cochlear implant because I started to enjoy sounds really and, like Robert said, I try to learn how to hear everything. For the first time in my life I truly enjoy sounds because I now have freedom to choose but now I think that it's very very important to talk about it to all my family, my parents, my friends about this change in my life and that's very important.

She went on to say in the chat room something her family used which aroused much interest to show when she was "switched on" and when she was "off" enjoying silence.

My children bought me a small lamp with different colors. 😊 They are so creative. 😊 When I am off, we agreed that I turn it red. When I am on but without my processor, I choose another color. It became our family communication system. 😊

The Conversation was then taken up by Darja, who first mentioned her topics and then indicated her daughter Zana would be contributing as well. Topics were:

- Hearing loss can affect quality of communication, relationships within family
 - Extra effort, frustration due to unclear understanding
- Children often develop their own adaptation strategies
 - Visual signals, patience, speaking slowly, looking at face
 - Sometimes just too much ... ignore parents
- “Third-party disability”
 - HL of one member affects entire family
 - Children assume role of communication mediators

DARJA: For those who don't know me, I lost my hearing as an adult, so since I was 23 and my 3 daughters lived with me; I didn't really think a lot about how my hearing loss affected to my girls, to my partner or to other family members. Somehow I adapted to my hearing loss and in that typical way, the worse my hearing became and the stronger hearing aids I needed, the more I withdrew from my environment. So, only when I became completely deaf and I moved to an implant I started to think about how my daughters could experience my hearing loss, not only in terms of adapting but how it affected them. I remember once asking my older daughter to write an article about that, and I must say that that article in fact woke me up, and I realised at that time that it was not only me, but also the people around me who were very strongly affected by my hearing loss. That was really, really big shock for me and I was thinking after that Oh, I was so selfish in one way, I was thinking only about myself. Not about my daughters, or people around me. So I am really glad that Žana, that is one of my daughters, today is with us and she's willing to share her view with you, even though she was a little girl in that time. I also remember that I relied a lot on my daughters after we were alone, I had to take on all communication and arrangements which was done before by my husband. We also need to know that 20 or 30 years ago there was not so much electronic access for communication. This was very stressful for me because everybody called me, called us, that was terrible.

Because we know about the experience of people with hearing loss and not so much about experience from children, I would like to invite Žana now that she share her experience about the misunderstandings and stress when you were involved with what happened to me. So Žana.

ŽANA: Yep. Yes, so when my mum asked me to do this I actually started thinking a bit reflecting on what happened when I was a kid and then thinking, because I am a psychologist, reflecting on how I am perceiving things now. I started remembering all the panic moments maybe my mum had when someone would call her because, I don't know, telemarketer or doctor or whatever, and she would rush into the living room or into my room or my sister's room, handing the phone like she doesn't understand and I was like, nine, ten at that point. And I would have to communicate on the phone while talking to my mum, not really understanding what they are telling me. So I remember it was how you have to grow up in that moment and understand what's happening. I know I was our Wi-Fi expert! I was always the one who had to fix the Wi-Fi, call for the Wi-Fi and it makes you understand more things about what my mum was experiencing. I also learned a lot. But I do see right now as an adult I have a bit of anxiety calling people because I don't want to do that anymore.

Also remembering how sometimes maybe embarrassed is a strong word, but if we were walking on

the street and my mum would do something unknowingly wrong and then some stranger would start screaming at her that she's doing something wrong, but my mum didn't know. So she would always just kind of walk away and it seemed like she's ignoring that person, even though she just didn't hear the people speaking to her and then I would have to go and kind of de-escalate the situation and telling them how she just doesn't hear. Right? I think in those cases it was kind of difficult and then seeing my mum withdrawing from social interactions was always hard for me. I had feelings of guilt, and being with family and my mum would just withdraw, erm, kind of hide herself while we were having fun and I always felt guilty about that. Yeah, those are some challenges.

DARJA: Yes. That is, it was very hard for me when I started to think about all the difficulties which my children have with me, in fact, and sometimes I know now that was just simply too much for them, and I remember also that school performance and all the sports events when you want to be included, like, the parent but I was not, in fact. I was there physically but I was not able to follow anything and I always asking to my daughters, what is going on? And they are explaining to me after the events about the main topics. And also when you start to think about what that really means of your child when a parent depends on the child, and on the child's interpretation of events and that was very, very stressful for me, and Žana, can you share your experience from this so when it was just too much for you?

ŽANA: Yeah. I guess what I mentioned before, just the strangers part. It was always the hardest because I didn't want to talk to strangers and I had to. A lot of times it would be difficult when I would call my mum with good news and I told her once and she didn't understand, I told her twice and she didn't understand. So I had to repeat myself so many times that good news became frustrating news. And it sounds awful, but I would just not call her with news anymore. I would call my dad or my grandma. I know my mum asked her mum to basically call us to explain things to us, which was I am sure difficult for my mum as well.

I also think about adaptations I would make, like if we went to a mall - I don't know how it is in other countries - but in Slovenia every mall has blasting music, so someone with hearing aids finds it very difficult to understand, or have a normal conversation while there's also music playing in the background. So I was mentally noting down things I want to talk to my mum and then I would do it when we were outside. Yeah, just some small things that, you know, looking back maybe they were not so small.

Third party disability: asking your children for help while trying to adapt to deafness

DARJA: I was the one to mention the third-party disability. I think this is so important point, in fact, because we need to know how hearing loss affects others and I feel that the focus is still mostly on how hearing loss affects people with hearing loss themselves. This area is not so well researched. The question is, do we ask ourselves how our hearing loss affects our family members? How they feel and how do our children feel when they have their parents? Do we explain things to them in the proper way? Or we just ask them, go for help. I said, Oh I am not able to hear. Can you help or just I gave the telephone but I didn't explain, Oh, do you know I am really, really upset about that. That is very important communication for me. We need to resolve this problem immediately. Can you help me? No, I just gave the telephone and when I try to explain sometimes to persons on the other side, OK, I have a hearing loss, they were not able to understand that I have hearing loss because I speak with them, and the more I repeat myself the more they need to explain to me and that was very, very frustrating situation and I can also say that during the period of my greatest hearing loss, we did not really talk about how this affected the children and the others. I was focused, as I said in the beginning, how this affected on me and what kind of feelings I had and I could say so many times I felt helpless, in fact, because I didn't know in that time any people with hearing loss. I didn't want to

join any community with hearing loss because I wanted to be normal person without hearing loss. So I didn't get any help, in fact and I needed to explain to myself about hearing loss, to my children, to my family, to my co-workers, and it was such a big population around me which needs to know something about hearing loss and I was in fact lost in that. So that was very, very stressful.

At one point, my younger daughter became seriously ill and her health was at risk, in fact, she could die in that time. And her doctor was available through electronic messages so the first visit had been arranged without problems, but later when they said you need to go to the hospital immediately, there was a lot of noise in the hospital and everything was very stressful and when the nurse called me and telling me what it was about. I still didn't know.

Zana was at that time 14 and she needed to explain to the doctors and the nurses to communicate with her and then she translating to me what they tell her, but it was very difficult because that was also specific things which a mum needs to know and that was very hard communication, and I cannot imagine how she felt in that time because that was very big responsibility to take, because that was a life in risk. So thanks to Žana very much, I'm so grateful.

ŽANA: I can tell you now that the doctor basically said that my sister was going to die because she got a flu, that mutated and went into her heart and I was the one who had the flu. So I basically thought I was going to kill my sister, which I guess in the different situation my mum would hear, but that was kind of a difficult part because, you don't really tell a 14 year old what's happening, right?

DARJA: When I had appointments with the doctors in that paediatric clinic, they were not able to understand that I have a hearing loss, that I am not able to communicate with them in the noisy environment, that I am not able to understand them and it was very difficult to explain them that situation. I felt so, so lonely in that moment and then I said to one doctor, OK, can we go in your office please? I thought that maybe in his office there is not such noise and I will be to hear.

ŽANA: I graduated with my bachelors degree and my family was so kind to organise my own graduation at home, where my mum lives. So it was very nice surprise. I missed graduation in the university but I got a better one at home.

Darja went on to discuss how parents should act:

- Acknowledge the challenge
- Be aware that HL affects communication, feelings
- Talk openly, honestly about it with your children
- Active listening and patience – inform
- Engage in conversations without rushing
- Use visual cues (hand gestures, facial expressions)
- Use Compensatory Strategies
 - Inform
 - Hearing aids, assistive listening devices, quieter environments
- Maintain eye contact with the speaker

That is very simple, that we need to communicate and explain our feelings, to explain what is going on with us, and also that we understand for children and other family members, that our hearing loss affects them and that we explain all the possibilities for good communication.

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At the end of the hour, the Conversation planners thanked the contributors for sharing their experiences, and for the attendees' generous support for the contributors via their chat room comments.