

CIICA Conversation: Measuring Quality of Life in CI Provision

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Facilitators: Kris English (USA), Lori Sammartino (USA), Teddy McRackan, (USA)
Observer: Sue Archbold, Coordinator, CIICA

Attendees from 8 countries: 7 users of CI; 2 family members and 3 clinicians. Live captioning was provided. Participants were from Finland, Ireland, Germany, Netherlands, Turkey, Uganda, UK and USA.

Introductions:

Facilitators: Kris is a retired professor of audiology; Lori is a teacher and now a coach with CI; Teddy McRackan, MD, is an ENT/Otorhinolaryngologist, with an interest in patient satisfaction and the lead developer of a well used CIQOL measurement at Medical University of South Carolina (MUSC) – posted on the CIICA website: [Cochlear Implant Quality of Life \(CIQOL\) Instruments for an Adult Assessment – CIICA \(ciicanet.org\)](https://www.ciicanet.org/CIQOL-Instruments-for-an-Adult-Assessment) Attendees also introduced themselves via the chat room.

Framing the Conversation

Kris English began by referring to the previous conversations on the topics related to Person Centered Care. The summaries of these conversations can be found on the CIICA resources page:

CIICA Conversations

- Adult Services After CI: Reimagining Rehab (April 2022)
- Person-Centered Care in CI services? (Feb. 2023)
- Moving on with Person-Centred Care in CI services (Sept. 2023)

She also referred to the CIICA Report- CI Services Matter which emphasized the need for lifelong, funded, person centred CI services [Report from our Global consultation with adult CI users: CI SERVICES MATTER – CIICA \(ciicanet.org\)](https://www.ciicanet.org/Report-from-our-Global-consultation-with-adult-CI-users-CI-SERVICES-MATTER) and then provided a working definition of Quality of Life in health care as "the degree to which an individual is healthy, comfortable, and able to participate in or enjoy life events."

The concept of QOL is inherently subjective and relies on self-report. QOL priorities will be different for different people:

For one person, it might be having enough financial security to enjoy some hobbies, free time or family. Another might be thinking, "I need more of a work-life balance," or emotional or physical well-being... but again, defined by the person who has been approached.

Compared to the traditional objective data obtained in health care (e.g., X-rays, blood tests, audiograms), Quality of Life (QOL) measures are personal, subjective views regarding current situations, and can add to or contradict traditional assessments. The main purpose of health care is to increase the well-being of those seeking help, and can only be achieved if patient views and priorities are incorporated to ensure health/medical care is fully evidence-based.

Lori then asked:

- What aspects of QOL are important to you/your family?
- Are they measured? How?
- Thoughts about the process/experience?

Financial Security

For several, financial security was important to quality of life, and a cochlear implant had helped to increase feelings of financial security:

...I think for me it definitely comes down to financial security.... retirement age for me is 67 and 3 months and I'm not sure if I would make it to that without a cochlear implant. And, well, not just one cochlear implant, but 2, and as I mentioned in the chat, that is something I'm campaigning for.

So the CI has allowed me to set a standard of, okay, this is the life that I can have, and I hope that it will stay that level for the rest of my career.

It was considered that the impact of CI (especially two) on quality of life should be considered by funding bodies, and the results of QOL assessments be taken into consideration.

I spend a lot of time thinking about the quality of life measurements that are done in the Netherlands because there is a strange reimbursement policy here where they only will reimburse one CI regardless of whether you need 2 because the quality of life measurement that are defined by the government says that one CI is good enough. It's sufficient for your life.

Advocacy Support

There was a discussion that for advocacy groups, if QOL was seen as important, then they were able to use these measures to advocate for CI:

It's giving us a vocabulary, especially for those of us who may not feel like we're well-equipped to advocate, that we can at least enter the arena now because of this language.

It's another issue that we need to address because this is so important and we need to make this information available in a way that politicians and funders will understand and appreciate and we can influence some of their decisions.

Personal Confidence

For others, the impact of CIs on confidence and communication was most important:

If I look back on the last 10 years, the quality of my life has improved mainly because of improved personal communication. I can communicate with anybody that I need to, that gives me reassurance that I can look after myself no matter what life throws at me, so in that way I feel that more important to me than financial security. I've got the confidence that if I get into a difficult situation, I will be able to get myself out of it by having the communication skills which I didn't have before.

Confidence in noisy situations and "living life" was important in considering quality of life:

I don't know how else you can measure it but I am certainly not avoiding noisy situations and I am enjoying noisy situations.

Biggest factor of quality of life I've had is getting back closer to where I was before I lost my hearing, to where I couldn't communicate anymore and just being a part of the hearing world that I grew up in. [That's] been the biggest quality of life factor for me: getting my friends and family back, being a part of things is what it's all about.

I played guitar in bands for decades and I was where I could not play and it took a bunch of effort, but I'm back playing guitar and having fun with it and it's been an unbelievable ride.

And for one person getting rid of tinnitus was the greatest thing:

One of the best things it did for me was it got rid of tinnitus which was such an overwhelming distraction prior to getting the implant.

Telephone Use:

Telephone use was not a direct question, but once it had been mentioned it raised a lot of interest and clearly mattered to the participants and had made a huge difference to their quality of life:

I have a phobia of telephones for the last 50 odd years. If the phone went I would run away from it. If I had to make a phone call I would let someone else do it. I used the phone accessory but I was finally updated and now I can suddenly stream phone calls direct to my phone and it feels like my phobia of phones has just quit overnight, it's gone. It's that transition that suddenly a phone doesn't scare me anymore. Is brilliant.. being able to feel confident in doing that too so that's probably another factor that definitely enters into our quality of life.

I think Bluetooth is the best thing ever, and I lost my confidence in using the phone in the run up over the last 10 or 15 years, you know, ... and now I'm telephoning everybody left, right and centre ... I can do phone calls for my mother who has hearing loss and not have to pester my brother, not having to pester work colleagues because I'm an audiologist so I need to phone clients - rather than just depend on emails - and I need to phone manufacturers etc. So now I'm able to do that... the confidence just took off within maybe 6 months of getting the cochlear implant.

I didn't talk on my phone for years. I just kind of isolated away and worked in my shop. I had to change what I did for a living... I'm back there talking on the phone. I work wherever I want to work.

Do CI centres use QUOL measures or ask about it?

Several attendees indicated they were not asked about their quality of life, and no assessments had taken place:

I've had my cochlear implant for 23 years and I've never been asked, I've never been given a form to fill in, I've never - even by my own centre - I've never been asked to fill in anything, so I think it's really good that we're talking about this (QOL) today

So, for example, my centre don't even know that I use the telephone. I've been using the telephone for 22 years now. So, how can we sell the idea of cochlear implants, get more people to invest in cochlear implants when we don't even have that data?

Where people had been involved in QOL assessment, this was really valued, as being recognised as important and:

So it's independence and a sense of agency is what it's given you?

Recognising Change in QOL Over Time

There was discussion about the value of using QOL measures over time, as the realities change over time.

I definitely was isolating myself pre surgery, because, yes, it just was too exhausting, too difficult, so, yes, you can't live life like that.

I think for me, my thought about what it was success going look like going in is way different now having come through it 3 and a half years.

One of the best things it did for me it got rid of the tinnitus which was such an overwhelming distraction prior to getting the cochlear implant. So now having been on the other side of it it's like, my definition of success is changing because I still struggle in noise or with multiple conversations and I know we all have unique journeys.

Measuring Quality of Life: Developing a Validated Tool

Teddy shared how the MUSC CIQOL tool had been developed involving users and using quantitative and qualitative research methods:

[The process started with] Cochlear implant users focus groups... understanding what matters to them, what impacts the implant had on their lives, what were the limitations, what really mattered to them. Surprisingly, it was the first time actual CI users had been engaged in this part of the research process.

We used the focus groups to create the bank of (questionnaire) items.. to develop the Cochlear Implant Quality of life Profile and Global instruments, and evaluated them against instruments previously developed to make sure they were validated and appropriate to use in cochlear implant users.

In 2020 we had this idea of creating the expectation instrument. This is an instrument that pairs with the Cochlear Implant Quality of Life 35 instrument, and it changes every item into

“I will be able to” Statement. This allows us to really understand how patients think they're going to perform with a cochlear implant before they get the cochlear implant, and allows us to measure that and we have normative data of how patients actually perform with their cochlear implant ...

Discussion took place about the need to use such measures to look at changes, and to influence rehabilitation and support, with Teddy reporting:

it's been used more and more and we're very pleased and have a lot of great research coming out about how to use those and help and improve patient care through using these instruments and focusing on them more than our traditional speech recognition measures

We're seeing fascinating things. We're seeing people who make incredible strides in the communication domain, yet they're still struggling in the social domain, still having lower score so we need to mature and provide whole person care to cochlear implant patients. Such as develop interventions that can help people, and ask about entering social environments because we see a lot of people who don't have that confidence. Despite the fact that, yes, they report doing well in these environments, they just have not developed that skill set to enter those environments, apply those skills in that environment.

One participant commented that these tools were useful for a base line then could lead to opening up about other issues important to the individual:

If you are really person-centred you're going to use any tool as a jumping-off point to explore further. In other words, we go through the items and we talk about them but then ask, “Are there other things you want me to know about?” and then you find out and work on those as well and not just on the numbers.

Participants asked Teddy about other areas which weren't included, such as the use of the telephone and support systems:

Did you have anything specific in your outcomes regarding employment or financial improvements in quality of life?

It looks like the focus is on the CI user but no focus on the families of the users. A CI doesn't just transform my life. It also transforms the life of my family and friends.

Is there a question that says something about having sufficient support in my family or my support system?

TEDDY: One instrument can't measure everything. This version is focused on individual user and their perception. ours is really a functional outcome assessment...Exactly what people have talked about today, feeling that whole person-ness, that confidence, we can use the instrument to identify people who score higher or lower on the scale, and then the question is why? We need to figure out who is scoring high on this and why, and how can we provide those same services to people scoring low? So, the develop of the instrument is at the beginning.

Summary

The characteristics defining “quality of life” are inherently personal, but we did identify some shared concerns among CI users, including improved prospects of financial security, increased

personal confidence in many settings, and a new comfort level with telephone use. The conversation ended on these encouraging notes: in some centers, CI users are being evaluated regarding Quality of Life concerns, and the evaluation process continues to be studied.

Future conversations will provide the opportunity to consider QOL from other perspectives, e.g., what would it mean to a CI user to be asked the open-ended question: “How is your CI affecting your quality of life?” One participant summed it up thus:

So I think in a lot of ways you can never have a good outcome or you can't really measure the quality of life accurately if you're not asking the right questions in the first place.

To access the MUSC tool: [Cochlear Implant Quality of Life Research Program | College of Medicine | MUSC](#)

Attached the slides from Teddy's talk.

Kris English, Teddy McRackan, Lori Sammartino, Sue Archbold, March 2023.