CIICA Conversation: Moving on with Person-Centred Care in CI services

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Observer: Sue Archbold, Coordinator, CIICA

Attendees from 8 countries: 8 users of CI; 2 family members and 4 were clinicians. Live captioning was provided. Participants were from Australia, Belgium, Canada, Finland, Italy Netherlands, UK and USA.

Introductions:

Facilitators: Kris is a retired professor of audiology; Lori is a teacher and now a coach with CI; Helen Cullington is Professor of Audiology at Southampton CI Center in the UK, and spent several years in USA. Attendees also introduced themselves via the chat room.

Framing the Conversation

This conversation follows the previous Conversations on Person Centered Care. Person and Family Centered Care in CI services as issues kept arising. Kris began with recap of previous conversations (full summaries available at www.ciicanet.org/events).

- Smoother, clearly defined pathways; shouldn't have to search for services
- Should be "bespoke:" personalised, flexible, self-paced, family-engaged
- Apply adult learning principles (adults use life experiences, want to choose how to learn)
- Focus on music, enjoyment, fun, engagement

What PCC means, looks like, feels like re: information sharing, decision making, ongoing rehab

- See person as a whole, not just a person with hearing loss
- Address social issues, build a personal relationship, provide regular appointments
- A feeling of team work, collaboration

July 2023 – Living Guidelines and CIICA input:

- Regular programming, rehabilitation: transition from HA to CI much greater than recognised
- Rehabilitation should include counselling, coaching
- Appointments should respond to user, individualised
- Lifelong rehabilitation should be available
- (NOTE: inclusion of persons' "voices" is not typical in healthcare reports)

A recent paper: Sturgiss et al. (2022). BMJ Open,12:e059400 asked:

It reviewed 159 scientific articles: 9 aspects of centeredness:

- Sharing power – sharing responsibility – therapeutic relationships
- Patient as a person – biopsychosocial – provider as a person
- Co-ordinated care – access – continuity of care

They concluded that the vast majority of studies lack patient perspective even with stated intentions of "increasing centeredness" which "leaves us wondering, whom is at the centre?"

Kris then introduced the Conversation with the questions from Lori and Helen:

- Lori: What was your experience like? Did you feel as if it was "***person-centred***"? Did it include shared decision making, personalized goal-setting?
- Were your family/loved ones included in the process, and if so, how?
- How do we advocate for ourselves?
- Helen: Tell me how CI centres could help you feel more involved in your care

Experiences of person-centred care

There were encouraging examples of person-centred care given:

Wonderful, great experience, my first implant was very successful. So I was fortunate to have been able to go over there.

What I likely learned joining groups like this or working with other people in the CI world, was that person-centred care wasn't really a thing yet. So I kind of made it all about me and just asked for whatever I needed. Luckily, the hospital that I worked with, is very receptive to that….. And I think that has made this whole journey a lot easier to get through.

They are flexible and able to accommodate what is needed and I, at first, was having trouble even wearing my device. So, you need to get over that hurdle to get any benefit from the CI and, if I wasn't wearing it, that was defeating the purpose.

Others had less personalized services with a lack of information which would have been helpful:

When I got my hearing device. I didn't get a letter saying what I could do, what was available to me, where I could go if I suffered distress or if I felt sick after surgery. There was simply no guidance whatsoever

But it was more like a one-size-fits-all, it wasn't individualised as far as I'm aware.

My experience is echoing that and the word rigidity is what I heard.

Person-centred care often had to be sought:

I think you don't realise how uncentred the care is until you find someone that puts you at the centre. And so, I'd gone for my whole life, as deaf, encountered a lot of professionals in the field, but it's only in the past few years I've met my latest audiologist and I say he's the best audiologist on the planet. And it's not just his skill with the programming, but the fact that he listens to me, works with me so intensely

So I've had to change my programming to different places and sometimes they've been good, sometimes not. Sometimes then the audiologist retires and you have got to find a new one.

Which could be difficult if you didn't know what it looked like, or consisted of:

I don't know if that is the common experience because, my situation, I didn't even know the questions to ask. And I don't know if the centres were educating me about it, it was something that I had to navigate my way through

I am also curious what it's going to be like after the one-year mark. Because the plan is quite defined for the first year. But after the one-year mark, it gets a little bit, well, there's really no plan, it's kind of like, just, I guess, if you need us, call us

And seeking other support or changing clinics required some courage:

I don't know that I was brave enough and I'm wondering if other people felt that too. To think I actually had the option to go outside the clinic or the centre and scaffold more supports that I would have benefitted from. So that really helped.

When I finally got brave enough to venture out of my assigned centre/clinic, I ended up with much more of a patient-centred focus at the university/college level with their Speech, Language and Hearing department. They were much more attuned to my needs and willing to invite me into the process.

Influences on choices

Experiences of person-centredness could be about more than the clinical care, depending on the health care system and funding systems. There was huge variation in this group in this area: for some (e.g. Finland) it was possible to change CI centres but for others no choice was possible:

Already the reimbursement system is not person-centred. I mean, in Belgium the family or the person who wants the cochlear implant can choose the CI team, but once you have chosen the CI team, it's nearly all the time the surgeon will choose the device. You have to go to the Deaf Fitting Centre and, even after ten years you cannot switch to another fitting centre, neither a rehab centre. Several of my persons that I know, they came to me asking, can I go to another centre because I'm not satisfied with that audiologist or speech and language therapist, or they don't have a psychologist on their team and I want that and so on. In Belgium, it's really hard to switch between teams because starting the reimbursement means that the CI team has signed an agreement with the Government of health care to taking care to take life-long care of this patient.

So that is a good thing and a bad thing. The long-term care is good but what if you need a change?

I'll say there's a whole bunch more issues regarding our care, other than just the audiologist and centre performing the care. There are also things related to insurance and the manufacturers and the

process that they require that you go through for the programming and mapping and all of that. So, some of my issues are more centred around those latter issues

It also sounds like there's some differences between the concept of choice and whether or not we are talking about implant brands, centres, so maybe we have more choices in America because, but that's just how our system is built, but we also pay out-of-pocket, you know, higher prices, to be able to get those choices. I don't know how much challenge you guys have that you are up against because you are dealing with the National Health Care system. I don't know how much you can tailor but good luck trying to get the patient-centred care even though you have to kind of follow that national government guideline.

Clinic Appointments

Experiences of appointments also varied. However, commonly the appointments are to a set schedule and the purpose of the appointment not always clear:

I've had my cochlear implants, for getting on ten years now, so I just have an annual appointment and I'm happy with the programming as it is. …….. It takes my time, my clinic's two hours away, so, you know, invite me there for a reason or agree with me why I'm going there.

From a clinician, reflecting on practice:

It's so interesting, over the years, we have started to talk about person-centred care more, and I must say that I'm guilty of this myself as well, that I think I've been guilty of making the rule so making my own definition of what is patient-centred. And I think of it now and I think, that's crazy, how can I say, this is patient-centred, you know?!

And:

I say to my patient, what do you want to get out of this appointment, but maybe that needs to be taken a step back because N is saying he's been sent an appointment and he doesn't even know what it's for.

I try to say at the beginning of the session, we've got an hour and a half, what do you want to get out of this session, what is important to you, what are your goals, what do you want from the this?

This approach was appreciated:

Just listening, it's listening to the patient and like H mentioned earlier, I think that is a good approach to ask at the beginning, what do you want to get out of this, what are your goals, and anything that allows the patient choices and preference so they can be satisfied that they're getting the care and the outcomes that they desire.

M says LISTENING, and yes, I agree! Step one, just ASK the patient at the start of the appointment how it's been going. How are they coming today? What do they think would be most helpful? If they don't ask, they don't know.

There followed a discussion on goals and discussions of mutual goals:

I'm wondering, with regard to clinical, how you might communicate with H, with the clinics that one works with? Would someone feel comfortable with saying, my goal is to sing with the choir and my

family, or my goal is to use a telephone conveniently without a lot of extra things or I don't mind using extra things but this is my goal, is everyone comfortable with that?

It would be good if the goals were agreed with me beforehand. Everything comes from hospital. They tell me, you have got an appointment, this date, this time, with no consultation with me about it. I'm a working man, I get an appointment, I've got to fit it in.

However, setting goals could be difficult if you didn't know what was possible and if audiologists did not discuss or enable some features that were possible:

I recognise that audiologists are the experts - but how do we know what can be adjusted if no-one is prepared to show us what can be adjusted?

At the beginning of having a cochlear implant, there's such a lot of information and I think the audiologist is rightly or wrongly, well I do it definitely, kind of gatekeeping that information. But yes, I don't know, maybe, I don't know how I can assess who can cope with making all these choices and who can't cope with it.

One experienced CI user:

We don't have enough time to make it person-centred for me to evaluate more of the advanced programming options that I want to have different programmes and change a lot of things.

And if the changes are not helpful in real-life, what do you do:

Once you walk out and you are in that situation with the background noise, you come to realise that uh-oh, this programming, I'm not fully satisfied with it.

The challenges in the systems

The challenges of providing personalized services in health care systems was discussed: audiologists and clinicians may wish to personalize the appointments but the confines of the system or the institution in which they work may mitigate against this

In cochlear implant centres like in hospitals, it's a big kind of machine that patients are progressing through, and it shouldn't be like that, but often things do follow quite a rigid pathway to make it easier for the clinic, I guess.

Health systems try to make you work in a way that runs completely contrary to the person-centred care approach,

Funding may be an issue as to what the appointment can address:

There are so many areas that maybe we need to start looking at person-centred services in different areas to address, like technology management, counselling services, PO groups, funding, because, I did put in there, health care funders everywhere in the world have to balance the books wherever it is, whether it's the challenges in India or Uganda or wherever, and tonight we have been in the US and Europe really, but many of those other areas have issues and it isn't an open-ended cheque book of funds for all the services that everybody would like to have.

And they could get more money from the insurance company to have it billed out as a programming appointment. So maybe we need a relook at how the insurance is billed out and I don't know what your NHS system is versus the US again.

Providing personalized appointments within our diverse communities is even more challenging:

How do we meet, or help those people feel at the centre of their care when actually, they are marginalised anyway within our community, within our country?

And for that, you need to go into different communities, you need to gain trust. So I think the trust is a big thing, isn't it, changing expectations.

Children and Young people and their CI:

The issue of person centred services for children was brought up – and the role that parents and family groups have in this:

How instrumental are parents in ensuring that the process is patient-centred for children?

It was felt that being able to advocate for one's own care was important for young people to learn to be responsible from an early age:

Because I think if we can instil in young people with CI at a very early-stage that they can be proud of their cochlear implant, they should not be ashamed of it, they can advocate for themselves, they can ask for things and be listened to and they'll carry that through their lives. But that has to start early. And I think it has to come from the audiology clinics

But when I was at university, I used to rely on my parents when I needed to make an appointment with the audiologist or maybe, you know, needed to order some batteries or maybe I needed some equipment. …….. and there are many people out there who're the same age as me who're not aware of the lifelong services necessary.

Involvement in programming and in real-life situations

There was lengthy discussion about being involved in programming, while recognizing the skills and expertise of the audiologist, long-term users in particular wanted to be involved using their experiences as a partner and using the possibilities of remote programming:

The audiologist is at work, the patient can be wherever they want to be, they can be at home, at college, at work, whatever works for them. It's such a great way of the patient being able to assess whether you have made a good difference to the hearing or not.

But they are still in control and making the programme changes, even if it's a remote visit.

She had this new software and she turned her computer and we actually walked through and she let me see the different functions of the programming options that she had. And now there are a whole lot more options available on that screen than I ever imagined or than they ever told me. So feel free to ask for that.

I saw in the chat somebody said they typically, I don't want to pin this just on the audiologists, but it's manufacturer, the way they make the devices where certain features are not automatically enabled.

We shouldn't have to have audiologists enable certain things, and if they forget and don't do it and then we have to wait three months for another appointment, why is that not automatically enabled? All the features should be just available and then the audiologist can tweak it or programme it. So that is frustrating.

My dream would be, you guys mentioned that all this testing is done in the sound proof room, well then there is other capability to do the remote programming, true that's not in a sound proof room, but I would love to see if our centres or audiology practices could have many a room that had different rooms or sections that would imitate a restaurant situation, driving in a car, watching TV, you know, having all these stations that are different experiences in our life. Like you said, you do all this testing in a sound proof room and you test 95%, you can hear everything wonderful and you walk out and you go to a family gathering or to a concert or to all of these normal living situations and you can't hear because how they tested you and programmed you was not real life. So let's doing for more real-life testing scenarios and programming scenarios.

One participant went to the lengths of buying a book about programming CI:

But when you start reading this, you realise the amount of parameters that audiologists have, which we simply are not told about. I would love to experiment with some of these adjustments. Things like the repetition rates and things like that. Maybe it will make no difference but I would love to try it.

Audiology training

A discussion about the training of audiologists highlighted the fact that in the USA for example, audiology training includes counselling modules and this was felt to be invaluable in promoting person centred care and a collaborative approach:

Our audiology profession would take a more counselling approach which could be considered the same thing as patient-centred care, but yet also listening and so much of hearing loss is emotional and depressing and stressful and traumatic, it's a loss, it's grief.

But we would love to see more counselling, psychological training with that, because hearing loss is, as you know, a very traumatic thing.

The challenges of this approach within the confines of an institution with the necessary protocols and funding limitations was recognized:

It used to be called non-professional counselling, just being a human being and being a good listener and being responsive and caring, it's expanded quite a bit. But I think what happens is, they have a course, they maybe even practise some of it in classes and clinic and then they go to an institution perhaps that becomes kind of like a machine and they lose the personality, they lose their own personhood and you don't see it in clinic.

In other conversations the role of peer groups and NGOs in providing some of the support necessary was recognized, and there was this comment:

In my opinion, the person doing the mapping does not need to be the same person who provides the psychological help/assessments. To my mind, these roles require quite different skillsets and personality types.

Information is crucial

A theme throughout was the sharing of information in accessible formats and in collaboration: clinics sharing information, and listening to information from the user and family:

Speaking from the Italian experience: person centred care is based on your ability to find the information you need, so that you can use your voice as a patient.

I think the most predominant thing that's come up today is just being informed. You know, like knowing at the beginning of your journey that if you have this, you think sign in for that, you can self-refer to this, if you have got this issue you can read that book from R. It's basic, like when you get an iPhone, you can go online and read the manual, can't you? Where is my cochlear implant manual?

We need to provide access to information and services that isn't intimidating, this is why responsible fb groups, peer groups are so effective in providing appropriate information and allowing patients to "raise" their voices.

Summary:

The conversation was wide ranging but the issues to emerge:
- There were examples of real person centred services
- These had to be sought
- In some systems there was no choice about service attended
- CI users wanted involvement in programming sessions
- Shared goal setting with enough information to do so was welcomed
- Information about the purpose of the appointment and some choice about it was welcomed
- Shared information is vital to ensuring the maximum benefit from the appointment
- Recognition that issues in real-life should be part of the person centred service

Sue Archbold, Kris English, Lori Sammartino, Helen Cullington, September 2023