

Perception of Treatment and Impact for People Receiving Hearing Implants

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Research: People's experiences of the process

- Living with hearing loss
- Expectations
- Getting the implant
- Rehabilitation
- Ongoing life

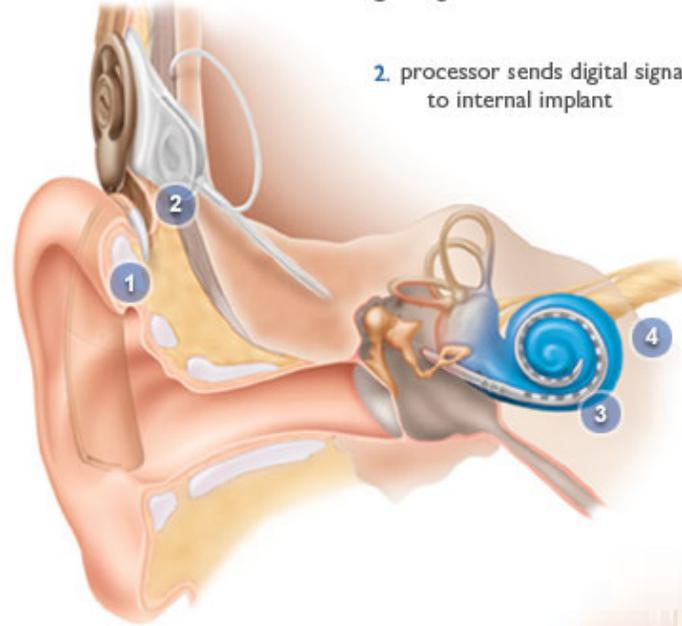
- Not a direct comparison of people's experiences with brainstem vs cochlear implants – full rehabilitation time varies greatly
 - Up to three years for CIs
 - Up to ten years for ABIs

Hearing Implants

- Cochlear Implant

1. external speech processor captures sound and converts it to digital signals

2. processor sends digital signals to internal implant



- Auditory Brainstem Implant

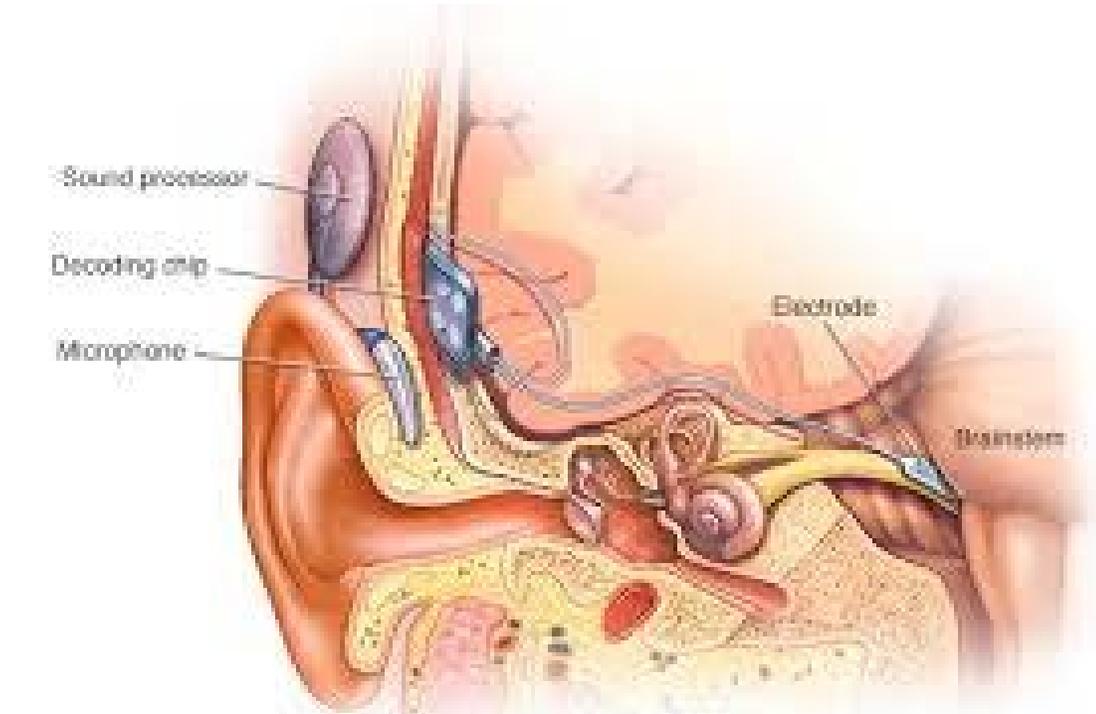
Sound processor

Decoding chip

Microphone

Electrode

Brainstem

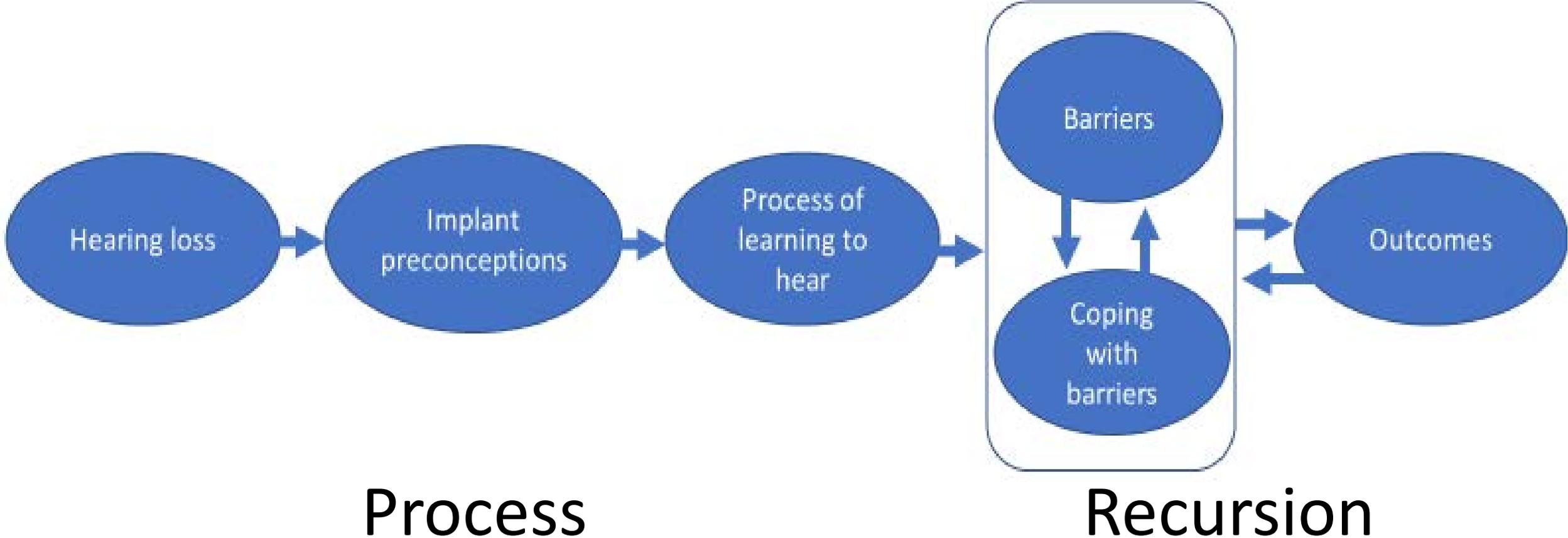


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Research

- Interviewed six people three times
 - Three got CIs
 - Three got ABIs
- Interview 1: Before implantation
 - How is life?
 - What are your hopes/expectations
- Interview 2: 1-2 weeks after mapping
 - How are you doing?
 - How was the clinical process?
- Interview 3: 3-7 months later
 - Has life changed?
 - What are your experiences?

Themes identified in the interviews:



Questions

- How did your experience of these stages differ from the quotes?
- And how was it the same?
- Did you experience other stages or perspectives?
- Could we help people to face these better?

Themes identified in the interviews:



Hearing loss

Hearing Loss

“Just cannot hear anything; I can hear sound, but I can’t decipher any speech”

“Often it takes me longer to decipher what’s happening”

“My speech is deteriorating, probably because you are not hearing properly”

“I will hear a noise, but I don’t know where it’s coming from”

Hearing Loss: Tinnitus

“It’s your brain filling a space, because your hearing is dropping, so it’s your brain compensating for that.”

“It just about drives you mental!”

“. . . years since I had a really decent night [sleep], so I get broken sleep and I’m sure most of it is the tinnitus.”

“Really scared that it was going to be forever”

Hearing Loss: Impact on Life

“Life has become hell for me [...] I have had no social life nothing, I can’t go out anywhere, I can’t listen to television, nothing”

“I did suffer with heavy depression for a long time which started when I first lost my hearing”

“I used to love music, [...] I can’t understand music anymore, [...] that’s one very sad thing really that I have lost music completely”

“You have to have someone with you and I’m actually quite an independent person, [...] frustration about my independence full stop has been a big issue”

Hearing Loss: Social Impact

“You feel you are missing out on things, because of a lack of hearing what is going on or being aware of what’s going on around everyone”

“I can’t communicate, I can’t carry on a conversation now because I can’t hear the other person”

“I’ll tell them I’m deaf, but I’m still like willing to talk [...]; they’ll get a bit weird and leave me alone”

Hearing Loss: Coping

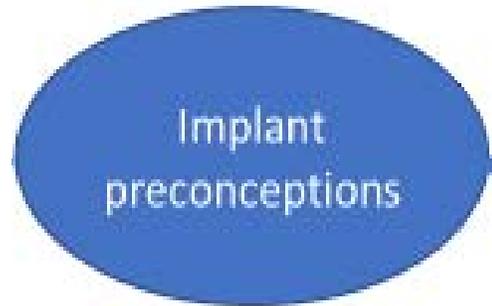
“You can get tired because you are concentrating more on your lipreading and trying to work out who is saying what”

“I feel the music: if I put my hand on the couch or table, I can feel the beat”

“Always on the watch, and you watch for people’s body language”

“If anything, it’s family I couldn’t cope without, because they do amazing things for me”

Themes identified in the interviews:



Preconceptions

“I hope to hear television. I want music if I can hear it, if I can participate in social life, church activities, it’s all things that I would love to do, which I used to do before”

“The implant not working, and I’ll be deaf for nothing because of how its irreversible, I don’t know how I’ll feel being left with a foreign object in my head”

“I think the frustrating part was waiting for the funding, the funding part was the holdup part but sometimes you keep thinking, how does the criteria work? Some people get in quicker than others”

“You've got to retrain your brain. I’m aware that there will be a lot of work involved to progress”

“It’s a long process, it’s not that you get the implant and switch it on and day one you are ready to hear”

“By God my brain is going to get a work out and it’s going to turn those beeps into words, so I can recognise and have some sort of quality of life”

Themes identified in the interviews:



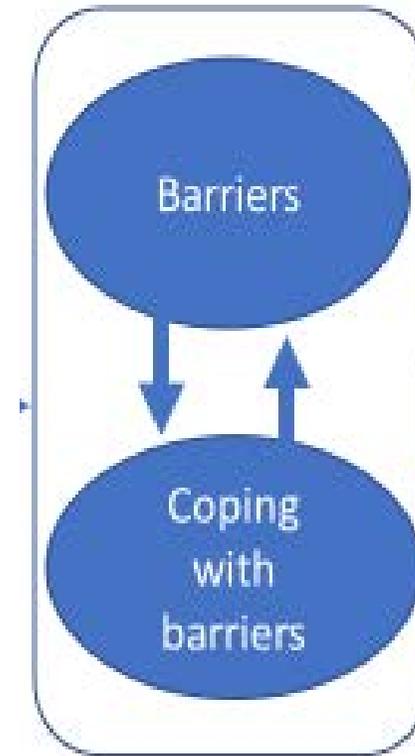
Learning to hear

“It seemed really strange having something out there after nothing for so long, and then the sound wasn’t as I imagined it, more like R2-D2 off Star Wars”

“It’s like being a baby and learning to talk, you didn’t learn to talk straight away did you, you know you’ve got to actually retrain the brain”

“Sometimes I’ll hear something I’ll just stop and think what’s that kind of noise, I’ll try to make out what it is and then I’ll walk around, and then ah there it is, and I make that connection with the sound, so next time I hear it I’m like ah I know what that noise is now”

Themes identified in the interviews:



Barriers: hard work

“You will work harder than you have every worked in your whole life before, and that you’ve just got to sit down every single day and concentrate and practice listening”

“It’s quite tiring because you are concentrating a lot, so they say the first couple of weeks will be quite tiring, because you are just getting used to all the “chipmunking”, overflowing sounds all the time”

Barriers: process

“Because you can’t hear, looking at faces, people looked like it wasn’t going well: and it wasn’t going well - one of their computers wasn’t working, but I thought it was my ABI not going well. Yeah, so it’s one thing I have to say there could have been better communication”

“Every time I go back, they fine tune everything a bit more and try and balance the sounds”

“Feel like I’m hearing the sound and interpreting it, and they would do all the tests and tune it. And I would go away, and “help I can’t understand anybody anymore!” because its changed and then, I feel like it was getting back to helping me, and then it would change a bit more”

Coping:

“For the first two weeks it’s been quite overwhelming, because everything is so new and trying to get used to that chipmunk [implant sound], and trying to persevere knowing that that will eventually go away”

“I’ve got my family backing me up, they always test me every second night to see how I’m going, so it’s nice”

“I can’t emphasise enough is the group chat with other people that have got the same thing if I didn’t have that you would be isolated you know like we share just funny little quirks that nobody else understands and it’s a huge part of the rehabilitation is having the support”

“They [friends] think it’s cool, they help me with my homework too when they come over and like make a lot of noise for me to hear”

Themes identified in the interviews:



Outcomes

Outcomes: Positive

“I can hear brushing my hair, I can hear wind, I can hear a little bit of traffic, I can hear the phone ringing now, so I think that’s amazing”

“I recognised my sisters voice and it turned out she was talking behind the closed door”

“I wouldn’t say 100% but I would say I’d put it down to 85%. I can’t catch every word you know but it’s a great improvement, I’m quite happy with that”

“Now that I’ve got the ABI, it sort of masks it [tinnitus], totally disappears”

Outcomes: Limitations

“In noise the implant doesn’t work so well. Noise blocks out speech”

“All I ask for is some volume, I feel like I’m a transistor [radio] and I’d like to be a boombox!”

“I met somebody the other day who said she had had hers for eight years and she didn’t like the birds and I don’t like the birds, they drive me crazy and the rattling of plastic bags I just can’t stand those

“There was a concrete floor concrete everything windows no carpet no anything to absorb the sound so I was I couldn’t understand anything”

Outcomes: Limitations

I think it's the accent of different people that I find difficult to catch. Quite often I've got to ask people could you please repeat"

"I think if I could use the phone, I would tell you that my life is perfect"

"Music doesn't make sense to me. Music is the last thing the brain will be able to adjust to, 'and don't get discouraged' she said, 'but you may never be able to recognise music'"

"I'm not picking up the speech parts yet, so I'm still relying on the captions"

Outcomes: Social

“To feel included is actually what makes you survive”

“It depends on the group like if it’s a big group its hard”

“The others actually they all cracked up laughing and later on I said ‘what did she say?’”

“I’ve started feeling more involved in conversations, even if it is a group, even if I’m not quite understanding what everyone is saying, I don’t know it seems to make me feel more involved”

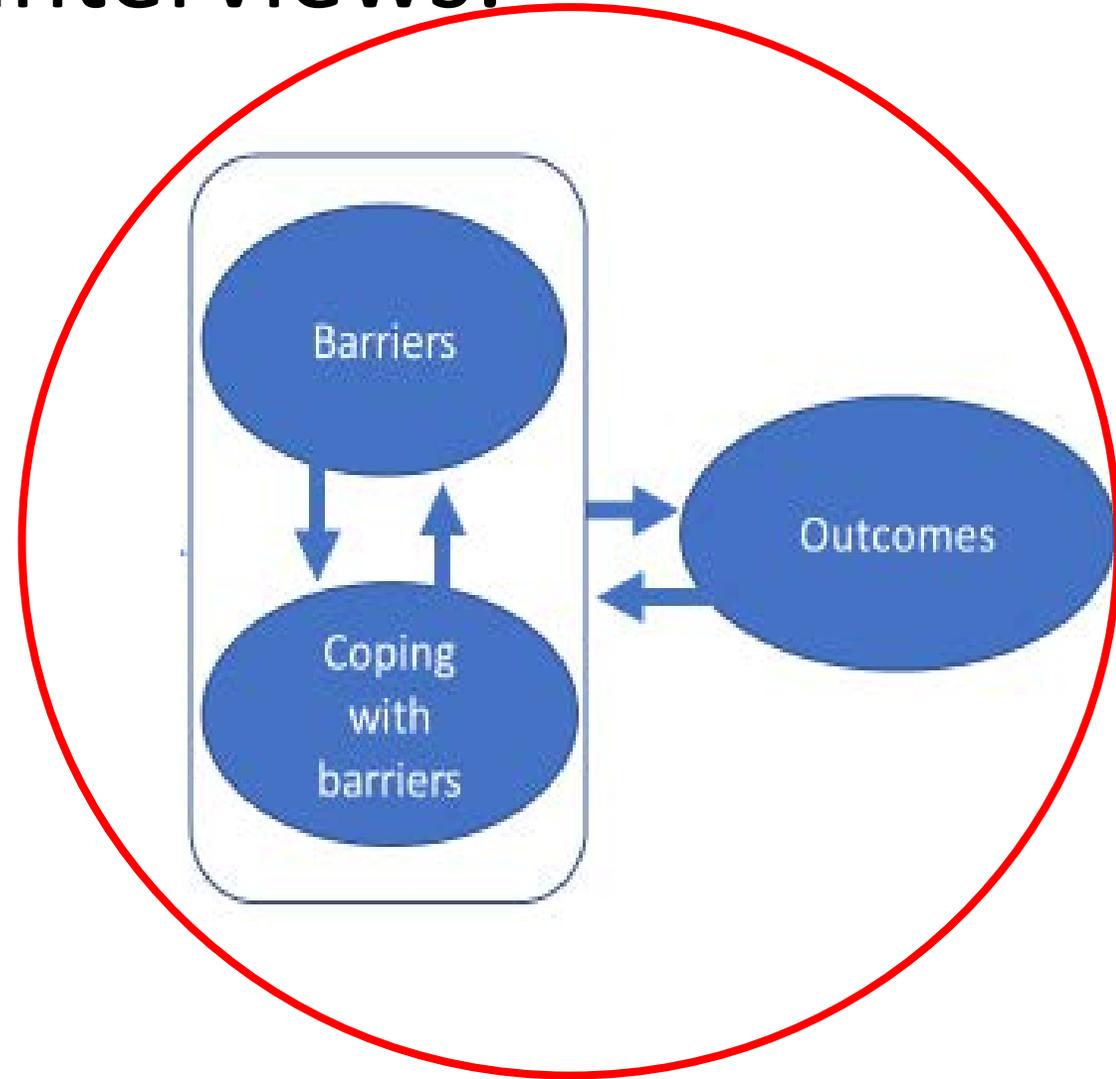
Outcomes: Self and Others

“Having the cochlear implant, I think is the best thing I’ve ever done because I’m realising how much sounds I’ve missed out on before I had it, so my confidence is a lot more and my emotions [are] stable, because I’m not worried too much about the future”

“I would say like a miracle to her that I could talk to her again, so much so that her blood pressure came down, she was more cheerful, it made a big difference in her life”

Themes identified in the interviews:

Ongoing
Management



Ongoing management

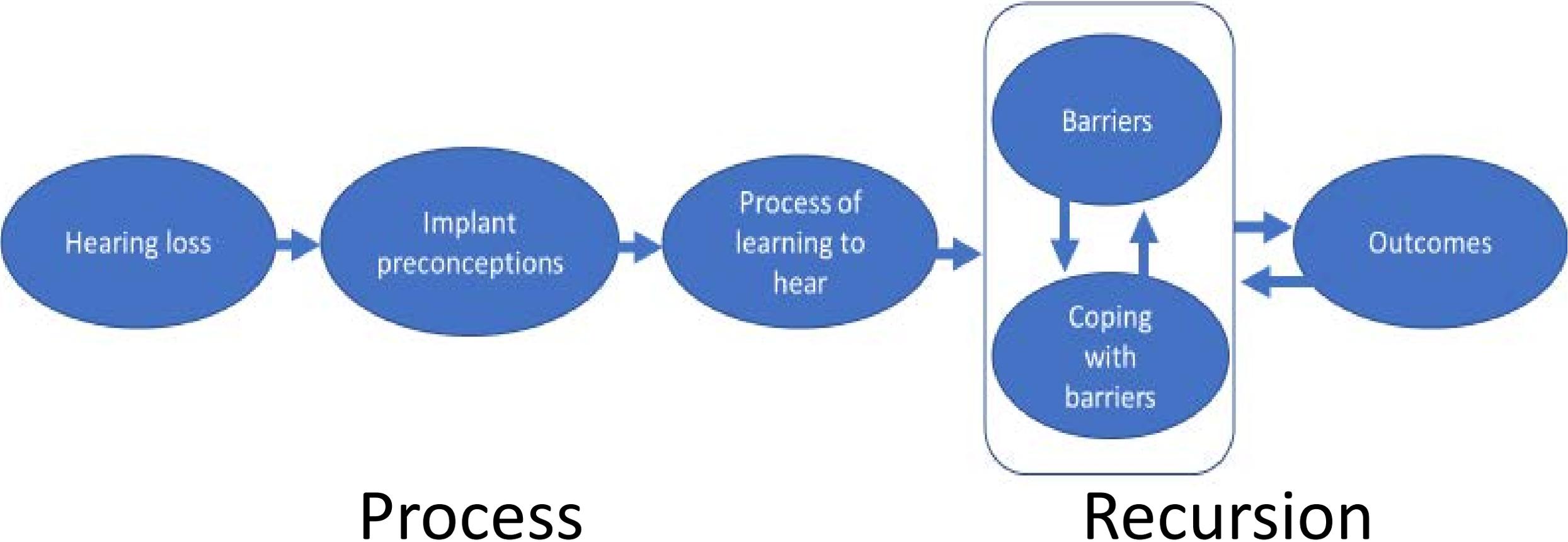
“You just have to make sure you get up the front, and try and make sure you hear the best you can, you watch body language”

“It’s hugely time consuming you waste a lot of time following things up and double checking”

“I’m only going to keep good people around me until I’ve mastered it”

“There are certain limitations with the implant so that’s why I always tell my wife to come around talk to me so I can hear her better no use talking to me from the back and then saying you didn’t hear me”

Themes identified in the interviews:



Acknowledgement:

Thank-you to the participants for their willingness, time and honesty in sharing their experiences

Questions

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- And how was it the same?
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