



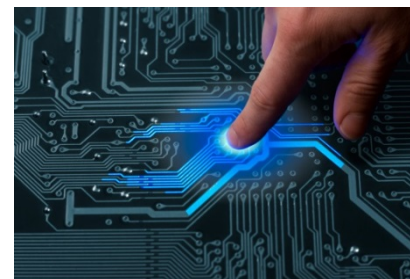
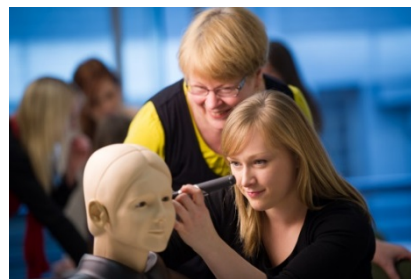
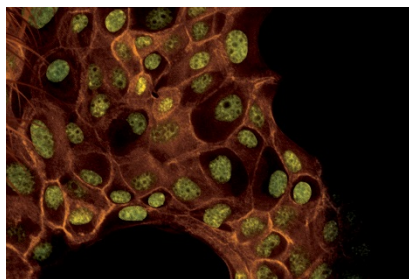
THE NATURE OF PATIENT- AND FAMILY-CENTRED CARE ACCORDING TO AUSTRALIAN YOUNG ADULTS LIVING WITH HEARING LOSS AND THEIR FAMILY MEMBERS

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Audiology Australia Conference, Sydney, Monday 21st May 2018

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Young adulthood (16-25) is a time of rapid development: (Arnett, 2006)

- Moving away from home
- Beginning tertiary study
- Entering the workforce
- Establish family of their own

More than 8000 young adults in Australia are living with chronic hearing loss (Australian Hearing, 2016)

Young adults with hearing loss have complex audiological needs:

- Challenging listening environments
- Changing vocational needs
- Active social/romantic lives
- Rapidly changing priorities

One approach to managing complex and changing needs is Patient- and Family-Centred Care (PFCC)

Pro:

- Higher satisfaction
- Lower morbidity
- Plenty of books and papers telling us what to do

Con:

- Different dependent on kind of disease (Hudon et al., 2012)
- Unclear whether models of PFCC will transfer across patient groups
- Many models developed in medical settings (e.g. Johnson et al., 2008; Laine, 1996; Rosenbaum, King, Law, King, & Evans, 2009; Stewart et al., 2014)

*“to investigate and define PFCC
as defined by 16–25 year old Australians
living with hearing loss”*

Follow on from previous study (to be presented on Wednesday)

Of 33 young people who had consented to be contacted, 10 agreed to an interview

- Eight female
- Range of ages from 17 to 25
- Eight over Zoom (similar to Skype)

Semi-structured interviews

- 25 to 59 minutes
- Also allowed young people to contribute by email after the interview

Transcribed and analysed using Constructivist Grounded Theory (after Charmaz, 2006)

Initial results sent to participants for consideration

- No responses from participants disagreeing with the analysis
- Any further comment from participants may be incorporated into further publication

Build the Relationship

Get the
basics right

Give me
the power

Be an
expert

Stress that their lives are different from those of children or older adults

- Feel that their needs are different

*“you don't just have primary school [...] teachers,
you have primary school, middle school, high school” (Felicity)*

Value consistent, acceptable and familiar sound quality and experience

- Hearing devices that work every time
- More likely to stay with what's familiar than accept new technologies

Want minimal risk of regression

- Happier with a conservative approach – small changes
- Value trials as a form of data gathering
- Assume that clinicians have access to previous settings/sound

“it's always under the proviso that it can be changed, that it can be easily changed” (Brendan)

Define their own problems and successes

Want enough information to make their own decisions

- History, tests, technologies, and other interventions
- Multimodal information particularly useful (verbal, written, experiential)

A lot of the time the audiologist wouldn't sort of say anything, I just do the tests and they'll say 'alright you're a fraction worse than you were last year' or 'you're about on par with where you were last year, and that's about it and we'll see you in a year's time' (Felicity)

Value having conversations with their clinicians from a young age

- Positive experiences build when this interaction happens from childhood

Describe rejection of technologies as a thought-out choice

- The benefits of a technology are weighed against the social, emotional, and opportunity costs
- Stress “No” as a valid choice

Expect their clinicians to be experts on hearing loss

- Treating hearing loss clinically
- Communicating with people with hearing losses
 - Want to use services like SMS, TTY, email
 - Notice staff yelling at other patients on the phone

Expect their clinicians to be experts on the technology

- Want clinicians to be able to adapt, not just adjust

“I have some funding ... that I wanted to use for ... a smoke alarm that I can use in other people's houses. ... [I]t was like, a baby monitor sort of thing, so then it picks up the sound of a smoke alarm. ... And, my audiologist's first thing to say is, ‘you know, you don't have a child so how can I approve a baby alarm for you?’” (Elise)

Expect their clinicians to be experts on the patient

- Keep good notes
- Read the notes
- Know what's going on in the patient's life

Expect their clinicians to be experts on the hearing healthcare system

- Create a service that works well
 - Reducing wait times
 - Maintaining administrative information, particularly contact details

*I want these things and I feel like my audiologist is not sure of them.
Is she supposed to refer me? [She's] supposed to know [...] more than just if I look at this site online. (Elise)*

- Wanted clinicians to be able to refer them to funding and advocacy services
 - University disability services
 - Social/peer support networks
 - Government support services

Once these three initial things are met, a relationship can form

Young people recognise that their clinicians have strong interpersonal skills

- They value clinicians who demonstrate interest in all aspects of their life
- Want to go into conversations without an agenda

“Well it's like real one on one conversation like they really go with what you're saying more than like any agenda they have” (Brendan)

Young people value clinicians who make time for patients

- Not just in the office – also talked about responding to emails, SMS, phone calls

Young people emphasised trust and support

- Want to feel that they can openly express their feelings and preferences
- Value clinicians who emphasise ability over disability

“It feels like she cares about everything.” (Georgia)

Young people described a range of negative emotions

- Withdrawing from interaction with hearing rehabilitation
 - Treating the audiology appointment like a chore
 - Not engaging in appointments and not wearing devices outside of appointments
 - Feeling guilty for not getting the most out of their devices
- Feeling “pushed” into decisions
- Feeling like their clinicians didn’t care

They ask you how you’re doing and that, but it feels a little bit like they don’t care as much as they used to when you were a little kid. (Charlotte)

- Losing hope for the future

Young adults with hearing loss have unique needs

- Different from younger children or older adults
- Different from each other
- Needs can change rapidly

Young people are able to and want to drive care

- Give information and respect decisions made
- Options aren't rejected out of hand

Young people respect their clinicians' expertise

- Also recognise their own expertise in what it means to be themselves

Building a relationship avoids negative consequences for the young person

- Increases feelings of engagement with appointments and devices
- May reduce rates of rejection of intervention

Build the Relationship

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right

Give me
the power

Be an expert

Development of a Minimum Data Set for a Needs Assessment Tool for Families of Children with Hearing Loss Transitioning to Early Intervention (an eDelphi study)

Australian professionals (Audiologists, Speech Pathologists, ENTs, Teacher of the Deaf, Social workers, Psychologists, Paediatricians,...)!

If you have experience and/or expertise in working with families and children with hearing loss in **Australia**, please help us identify what to include in **Needs Assessment Tool** for families of children with hearing loss by completing a short online questionnaire (approximately 8 minutes):

<https://bit.ly/2GQeDTX>



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Members + Acknowledgements



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