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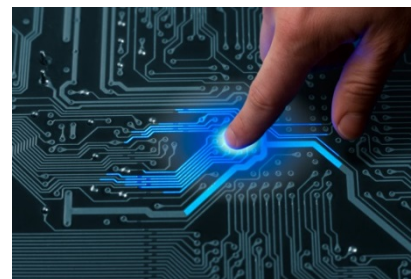
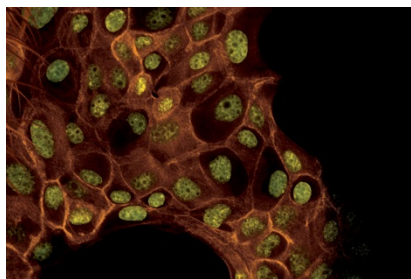
THE ROLES OF FAMILY MEMBERS IN AUDIOLOGICAL REHABILITATION OF AUSTRALIAN YOUNG ADULTS LIVING WITH HEARING LOSS

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World Congress of Audiology, Cape Town, 30 October 2018

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Most young people with hearing loss diagnosed early in life

- Initially mothers primarily responsible for rehabilitation (Erbasi et al., 2018)
- Over time responsibility for rehabilitation transfers from parents to the young person
- Unclear how mothers experience this

Aim of the study:

*“to explore the narrative of hearing rehabilitation
of mothers of young adults with hearing loss”*

Narrative inquiry (Clandinin & Connelly, 2000)

- Focuses on the stories that people tell
- Narratives are more than just stories
 - Also the social and cultural context in which these stories are lived and described
- Applications in health research (Wang & Geale, 2015)
 - We are characters in patients' narratives
 - By understanding narratives, we can know which character we are playing
 - We can also help “steer” the story

Four mothers of young adults with hearing loss recruited from a previous study:

- Anna – Amelia (17) diagnosed at 3 years, studying a Bachelor degree
- Colleen – Charlotte (18) diagnosed in primary school, studying a Bachelor degree
- Iris – Imogen (17) diagnosed in primary school, studying Year 11
- Janet – Julia (24) diagnosed at 3 years, working full-time

All young adults living at home

“Could you tell me about your daughter’s hearing loss?”

Conversations recorded and transcribed

Transcripts read and important utterances organised into a “script”

Major plot points of the shared script determined

Chronic Sorrow (Burke et al., 1992)

- Originally parents of children with congenital cognitive impairment (Emde & Brown, 1978)
- Non-pathological reaction to trauma
 - Initial trauma (diagnosis) causes grief reaction
 - Parent focuses on getting the child what they need
 - Grief can never be “put aside”
 - Parent repeatedly experiences episodes of grief

The Quest Narrative (Frank, 1995)

- *The Wounded Storyteller*: Restitution, chaos, and quest narratives
- In quest narratives, the person grows due to their health condition
- Quest narratives have a goal or “grail”, although the goal may be unclear

Diagnosis: Guilt and Trauma

Finding strength in rehabilitation

Becoming an outsider

Receding into the background

Central event: diagnosis of a hearing loss

Diagnosis as a traumatic event

*“I just assumed it was grommets. I hadn't even entertained any other possibility.
Just to be told that, point blank with no preparation time ...
I mean, how do you ever prepare for something like that? I was devastated.” (Colleen)*

A sense of guilt at not having “seen” hearing loss in their child

*“It was a bit rocky to start with because we sort of felt really guilty
that we hadn't realized there were problems with her hearing.” (Iris)*

Grief for their child's lost future

*“Honestly for probably three days, I cried. Because it was just
‘How is the world going to treat her?’” (Anna)*

Central event: transfer to a rehabilitative provider

Rehabilitative audiologists empathetic and caring

“She was the person I would have liked to have been my first point of call rather than the child health centre. [...] Rather than them doing the hearing test there and delivering the blow there.” (Colleen)

From early in rehabilitation process, child the focus of the audiologist

“I’ve been really pleased with them. They talk to her rather than to me. Even from when she was really little, which I found really impressive because it’s about her, it’s not about me.” (Anna)

“We had [audiologist 1] to start with, and she was fabulous. She was actually instrumental in making sure that she managed her hearing aids and all that sort of stuff. So, we still don’t know how to change the batteries and all that sort of stuff because she’s done it all.” (Iris)

Central event: focus of care moves to the child

Mother begins to feel like an outsider

“When you went to those appointments, you felt like you were a bit of an outsider. [...] They didn't really ask me any questions, never asked how it was at home or how she was coping at school.” (Janet)

Not a negative: assertiveness and independence for the child

“It's not that I'm not involved. I wish for her to be happy and to be able to manage herself. And if she wants me more involved, I will. And if I'm not, if she doesn't want that, that's fine too.” (Anna)

A lack of support for mothers, emotionally and informationally

“All the support went to my daughter, I must admit. [...] There was nothing really provided for parents and how to cope with it and where to go and what to do.” (Janet)

Central event: being an observer of the child

Hearing loss is hard

“She copes with it, but she doesn't really. I mean she does, but the older she's getting, the more she's articulating how hard it is and she's just had enough.” (Anna)

Expectation of catastrophe and role as support

“If something went wrong or she wasn't confident, or she had anything major that needed to be decided, we would support her in that obviously.” (Iris)

Diagnosis is traumatising

- Delivery of the diagnosis is a pivotal moment
- Early diagnosis may reduce guilt
 - Newborn Hearing Screening vitally important

The “grail” for the mothers’ quest is their child’s independence

- Mothers “divest” themselves of power and control
- Independence trumps their own needs

Child focus exacerbates chronic sorrow

- Direct: feeling like an “outsider”
- Indirect: seeing ongoing effects of hearing loss
- Recommended treatment is recognition and support

If you are involved in diagnosis:

- Practice delivering bad news
- Get training if you can (e.g. SPIKES/ABCDE/BBN)
- Peer review/roleplay communication

If you are involved in rehabilitation of a child

- Focusing on the child is the right thing to do
 - Establish child as the focus early
- Actively include the parent as well
 - Second opinion on problems/successes
 - Include in informational counselling
 - May be helpful to establish parental goals separate from child goals

If you are involved in rehabilitation of a young adult

- The parent is likely assessing behaviour and relationship
- Make the parent aware that they can trust you
- Maintain avenues of communication with the parent
- If the parent is present, actively invite their opinions

Mothers care and want what's best for their child

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Members + Acknowledgements

MEMBER ORGANISATIONS

		 MACQUARIE University	 sivantos the hearing company	
	 audiology australia ltd	 Bionics Institute	 Hear and Say Opening worlds for deaf children	
 h hybrid electronics	 Murdoch Childrens Research Institute <i>Healthier Kids. Healthier Future.</i>	 NAL National Acoustic Laboratories	 Neuromonics Tinnitus Treatment	 Neurosensory
 Royal Institute for Deaf and Blind Children	 E+3 the royal victorian eye and ear hospital	 The Shepherd Centre Giving deaf children a voice	 SCIC	 COCHLEAR IMPLANT PROGRAM An RIDBC service
 Taralye The oral language centre for deaf children	 THE UNIVERSITY OF QUEENSLAND AUSTRALIA	 University of Western Sydney	 University of Wollongong	 vicdeaf <i>Communication is the key</i>

Thank you to all the mothers in my study, and a special thank you to my Mum.



Australian Government
Department of Industry,
Innovation and Science

Business
Cooperative Research
Centres Programme

This study was conducted under the HEARING Cooperative Research Centre, established and supported under the Australian Government's Cooperative Research Centres (CRC) Program. The CRC Program supports industry-led collaborations between industry, researchers and the community.

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