An Illness Narrative of Pediatric Cochlear Implantation: A Case Study

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We conducted a qualitative narrative case study to determine the types of stories that adult cochlear implant users share

Narratives

- Stories shared by individuals about their own life and experiences

Illness Narratives

- A type of narrative shared by someone living with an illness or health condition
- Can discuss the personal and social aspects of the illness
- A long history of qualitative research gathering illness narratives (e.g., Harter et al., 2005)
- There are currently no illness narratives about hearing loss or cochlear implantation

Cochlear Implants (CIs)

- Biomedical device surgically placed in and used by individuals with severe-to-profound hearing loss
- CI processes sound externally, then produces an electrical signal that most individuals perceive as sound
- Created to give someone with hearing loss the option to hear in a predominantly hearing world

CI developers intended them to be a revolutionary product that would help people with hearing loss listen and speak. Outcome data shows that the devices do just that (Coez et al., 2008). Kids who got CIs early in life often excel in reading, writing, and language (Ceh et al., 2013).

BUT no one has checked up on these pediatric CI users to learn about their perspective and experiences growing up with CIs.

Our study & findings

Methods

- Solicited an illness narrative from an adult CI user implanted in childhood
- 1-hour interview with narrative prompt
- Audio recorded interview and transcribed
- Reviewed transcription
- Thematically analyzed narrative to identify the story type

Narrative Prompt

“Tell me the story of your experiences with cochlear implants. During your story, I’ll remain quiet until you reach the end. There’s no right way to tell your story, but I’m interested in hearing about it from the beginning, and then step-by-step until the end—present day...”

Aaron’s Background

- Born bilaterally profoundly deaf
- Born to hearing parents, no family history of hearing loss
- 14 months old when first implanted (right side)
- About 10 years old when received the second implantation (left side)
- Learned American Sign Language, and received speech therapy and hearing therapy growing up
- Support system
- In his 20s, receiving higher education at a university

Types of Illness Narratives

- Restitution Narrative
- Chaos Narrative
- Quest Narrative

Exemplars

Aaron’s Interview, Exemplar #1

"I don't have to worry about what other people think. What matters is what I think. Um, you know, yeah, I have difficulties, but that doesn't prevent me from living a pretty standardly normal life. Um, you know I listen to music, I was in band in junior high school, um, and in high school. You know, it was awesome."

Aaron’s Interview, Exemplar #2

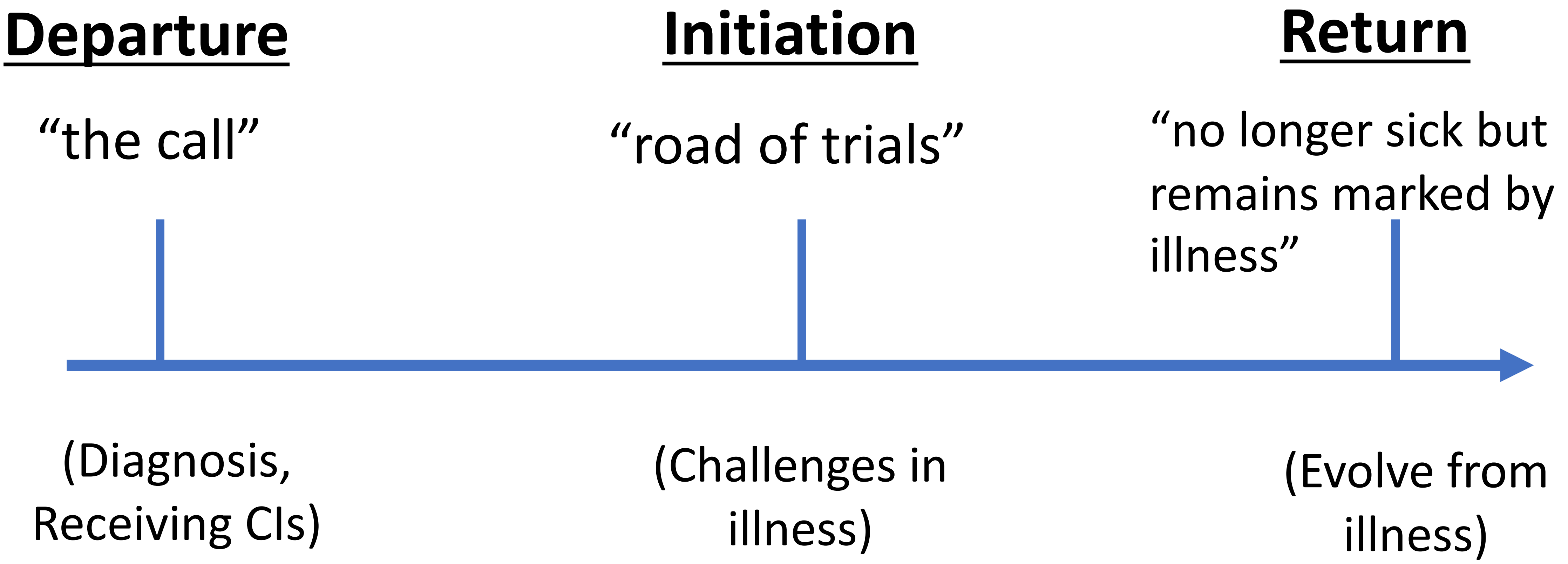
"I remember writing about how I always felt like torn between two...two roads, ya know? Like I always felt like I was in the middle of two worlds, and I wasn't really a part of one. I felt like I was hopping back and forth, ya know, between the deaf world and the hearing world.”

"And I just decided like, ya know what? I'm gonna work on making a bridge here. And, um, ya know, part of that is coming up with something that works for both sides, in terms of cochlear implants."

Aaron’s Interview, Exemplar #3

"I decided it would be super cool if, for my profession, I could work on developing cochlear implants. Um, so that's actually what I'm studying for right now. I'm a biological engineering major. Ya know my goal is to work with advanced bionics. And develop cochlear implants, test them”.

Aaron’s illness narrative fits that of a Quest narrative type.



Departure

“the call”

(Diagnosis, Receiving CIs)

Initiation

“road of trials”

(Challenges in illness)

Return

“no longer sick but remains marked by illness”

(Evolve from illness)

What Do We Know Now?

- CIs were created to be good speech and listening devices, but we don’t know holistically how this has affected them or who these kids have grown up to be
- If we’re going to have an efficacious device, we would want to be able to see how they affect them as they’re an adult
- This is a good starting point to find who they are and where they are now as CI users
- Aaron’s story has shown us that like other illness narratives, the quest narrative is an impactful one that has shown us that he has been resilient, despite of his challenges

- BUT we need more stories

Significance

- Helps researchers to better understanding holistic long-term effects
- Beneficial for healthcare providers
  - Provide parents with severe-to-profoundly deaf children insight to first accounts of what it is like to grow up with CIs
- Beneficial to families for making a choice to receive CIs

Thanks!

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