Tales from the Other Side : story telling in clinical settings

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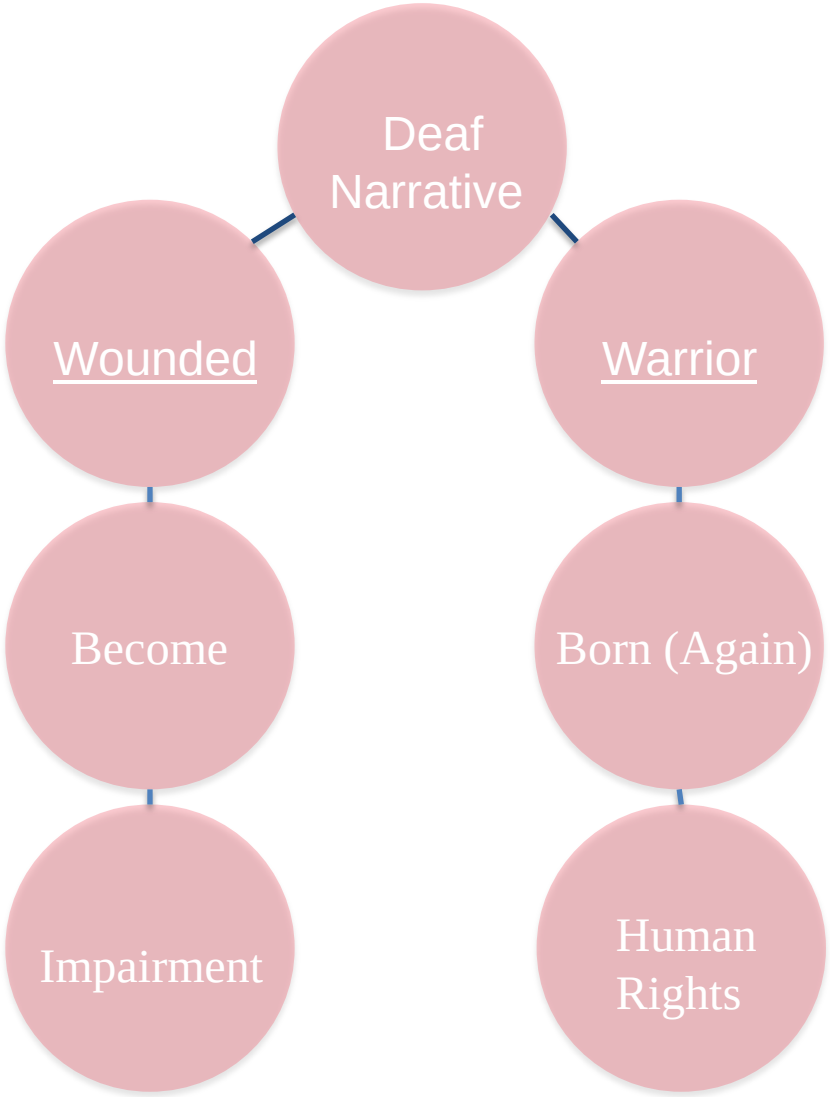
Introduction

- How do people talk about living well when they have a hearing loss?
- How can we listen to their stories in clinical settings?
- How does time and the completion of tasks, such as testing, fitting and selling affect this process?

Wounded Storyteller

- Arthur Frank
- Illness narratives
- Chaos
- Restitution
- Quest


Deaf Narrative
Wounded
Warrior
Become
Born (Again)
Impairment
Human Rights

Wounded

Chaos

I could have quite happily strung myself up when I first went deaf. If I'd had any sort of courage I would have. I couldn't see that I was going to be any sort of mother to them, I couldn't understand them. Something that really brought it home to me happened – I was sitting here, we'd had breakfast… [one child fell down the stairs and came in crying with his nose bleeding] I'd not heard and he'd had to pick himself up to come and tell me.

British Woman in early 30's.

Quest

I used to feel I was deformed. It's a deformity, something to be ashamed of.

Later she changed her view to:

now I class it just as wearing spectacles, what's the difference between having bad eyes and bad ears?

British woman in her 30's.

Restitution

"We want the hearing person I once was back again because she had control of her life. We think that this is all happening because of some tiny fault in our ears. But we aren't faulty people, if we could get our hearing back all the problems would go away. So we shop around for cures for a bit until finally giving up except to monitor cochlear implant experiments.

...We are stuck with pathological models and medical definitions of who we are when in reality we are not sick or ill people."

Wounded Stories Focus On:

Damage - loss and limitation

Exclusion - from Deaf and hearing worlds

Integration - re-assimilation or 'passing'

Not on Living Well but on a Deficit Model

Wounded network

ENT/audiological physicians
Audiologists
speech and language therapists
educationalist (teachers of the deaf)
Hearing aid manufacturers
Bio-tech companies – cochlear implants
Geneticists
Genetic counselors
Lip reading teachers
Lip speakers
Computerized text system operators and manufactures
Environmental aids manufacturers
Social workers

Warrior

Human Rights

Deaf people should get together and tell Governments about their situation… I would like the Government to treat Deaf people the same as hearing people. I don't like to see them thinking that to be deaf is also to be unintelligent – inside we are all equal.

Portuguese man 40 years old.

Warrior Stories focus on:

Fight - for Human Rights and Citizenship

Belonging - to a Nation, Culture, Community ,Ethnicity
Trans-national relationships World Federation of the Deaf

Separatism - Segregation, Linguistic Minority

The two narratives have different relationships to medicine/audiology.

Warrior stories reject medicine and use other discourses

Wounded stories embrace science and medicine

Techno Medicine

Wounded		Warrior
Cure	**Cochlear implants**	Gun (sign)
Repair	**Surgery**	Eradication
Prevention	**Genomics**	Genocide
Life-line	**Amplification**	Interference
Support	**Audiology**	Surveillance

Changing Narratives

Biotechnologies may ‘get rid of’ born deaf people

Deaf communities may weaken - integration

‘Text’ technologies - break down barriers

Perceptions of repair

Fixing things “broken ness”

Mechanical repair image of medicine

Associated with active agency /labour

Concept of restitution (Frank)

Body and technology

Bionic ears
Cochlea implant
Surgery
Prosthetics
Hearing aids
Cyborgs

Deficit Models

To be culturally Deaf is to choose to not read one's body as 'limitation.'

To be hearing with the assistance of a hearing aid or a cochlear implant is to be aware of one's body as a 'limited'.

Person-centred Care

Communication skills in medical training – simulated patients

Narrative-based medicine

Communication skills in Audiology training

Information counseling and emotional counseling

Calgary-Cambridge

Initiating the session
Gathering information
Physical examination
Explanation and planning
Closing the session
Agenda-led, outcome-based

Structure

Building a relationship

Developing rapport

Using appropriate non verbal behaviour

Involving the patient

Providing structure

making organisation overt

Attending to flow

Understanding the patient's perspective

Ideas – "If you don't know it doesn't matter." Physical attractiveness.
Concerns – "Adult diapers"
Expectations
"I want to hear the wheels of the world go round."
"Makes the world hum more."

Calgary Cambridge Competencies

Initiating the session

Greets the patient and obtains patient's name.

Introduces self and clarifies role.

Identifying the reason for consultation

Uses an opening question to identify the issues.

Listens to the opening response without interrupting or directing.

Checks and confirms the list of problems.

Negotiates to set an agenda for the session.

Process and skills

Exploring the patient's problem

Facilitates responses by verbal and non verbal techniques.

Picks up and responds to verbal and non verbal cues.

Clarifies statements.

Uses open and closed questions, appropriately moving from open to closed.

Listens attentively, leaving the patient space for thinking before answering, and continuing after pausing.

Summarises to confirm own understanding before moving on.

Encourages the patient to tell their own story.

Uses clear language avoiding jargon.

Is it any good for me ?

Open questions – Why do you think you are doing so well?
What does the person in front of you want in terms of living well?
What can you realistically offer ?
How can you negotiate and reach an agreement on a management plan ?
Can you use the method in teaching ?

References

Calgary Cambridge Website http:www.skillscascade

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Frank, A (1995) The Wounded Storyteller: body, illness and ethics, Chicago: University Press

Thank you!