'In the world, but not of it.': exploring the impacts of hearing loss stigma

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what is a stigma ??

- the word stigma comes from ancient Greece. *Stigma* was used to describe the cuts and burns inflicted upon people deemed to be deviant
  - attributes that are deeply discrediting
  - a difference, a discredited (or discreditable) attribute, a sign of deviance from “normality”

Goffman, 1963
the definition we use

“stigma is the possession of, or belief that one possesses, some attribute or characteristic that conveys a social identity that is devalued in a particular social context”

Crocker, Major, & Steele, 1998

dimensions of stigmas

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Expression</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concealability</td>
<td>how apparent trait is to others</td>
<td>having once been incarcerated</td>
</tr>
<tr>
<td>Course of the mark</td>
<td>if mark becomes more apparent over time</td>
<td>Parkinson’s disease</td>
</tr>
<tr>
<td>Disruptiveness</td>
<td>does trait interfere with social interactions</td>
<td>hearing loss</td>
</tr>
<tr>
<td>Aesthetics</td>
<td>level of unattractiveness</td>
<td>people who have had a limb amputated</td>
</tr>
<tr>
<td>Origin</td>
<td>perceived responsibility of individual acquisition of trait</td>
<td>teenage mom</td>
</tr>
<tr>
<td>Peril</td>
<td>perceived danger of the stigma to others in the social setting</td>
<td>AIDs</td>
</tr>
</tbody>
</table>

Jones, 1984
stigma: a social construction

- Occurs when two groups of people exist:
  - insiders (have trait)
  - outsiders (do not have trait)

- A label attached by and defined by society
  - In social settings, stigma may occur when outsiders relate an attribute (held by an insider) to a stereotype
possessing a stigma can result in *self-stigma*

- individuals who possess stigmatizing traits may direct prejudicial attitudes inwards

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Acquired hearing loss

- In Canada – hearing loss affects approximately 4 in 100 Canadians.
- Affects less than 1% of persons under the age of 25 years of age (National Council on the Aging, 1997)
- Prevalence increases with age – about 33% of people over 70 years of age most commonly reported chronic disabilities for older adults (Davis, 1997)
stigma and hearing loss

• present day stereotypes about *acquired hearing loss* date back to ancient times and attitudes held against people who were *deaf*.

• Aristotle wrote that people who could not hear were speechless, and most likely senseless.

• **the general public is unable to distinguish between manifestations of deafness and manifestations of hearing loss**

stigma and hearing loss

• people with hearing loss are sometimes perceived as:
  ◦ old
  ◦ cognitively diminished
  ◦ poor/uninteresting communication partner

Kochkin, 2007
why should we care ??

- maladaptive responses to stigmatization can result in shame, reduced self-esteem, depression
- stigmas can result in participation restrictions, and serve as an obstacle to help seeking

stigma and hearing loss

40% of people with hearing loss who do not use hearing aids give stigma as one of the 5 main reasons for their decision

- do not admit hearing loss in public – 35%
- hearing aids too noticeable – 35%
- too embarrassed to wear – 34%
- hearing aids make you look disabled – 31%
- makes you look old – 31%

Kochkin 2000, 2007
Stigma: A negative and a positive influence on help-seeking for adults with acquired hearing loss

- To better understand how stigma influences the help-seeking activities of adults who acquire a hearing loss in adulthood.

Methodology

- Qualitative description
  - Sought to understand participant experiences and describe in everyday language
- Participants:
  - hearing health advocates & volunteers (n=11)
  - Age range 53 to 76; 8F 3M; majority profound HL; 5 CI users
- Interview about help-seeking and stigmas
- Thematic analyses – to identify recurring themes arising in interviews

Three themes served to influence help-seeking

- **Build-up of stress:**
  - following onset of hearing loss

- **Critical juncture 1:**
  - numerous losses in valued activities lead to intensification of help-seeking

- **Critical juncture 2:**
  - when positive energy prompts advocacy work and new learning opportunities

“I had a grandmother who was from Vienna, who said, “I will be in my grave before I let my granddaughter wear hearing aids.”

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“It’s like a triangulation of events happened in my life all at the same time. The stapedectomy didn’t work. My mom who was living with me passed away and I lost my job and all within a three-month period. Boom boom boom. And I went into a deep depression…And I reached out and got some psychological counselling.”
Three themes served to influence help-seeking

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"Every time someone (new) comes, … All the emotions that I went through, …is mirrored back to me. It almost makes what I went through worthwhile, because now there is a reason why it happened to me. Because now I'm having an impact on someone else in a positive way. It feels wonderful."
Factors that influence disclosure of hearing loss in the workplace

- To identify the factors that lead individuals to conceal or disclose their hearing loss in the workplace, including
  o facilitators versus obstacles to disclosure
  o factors associated with these behaviours

Methodology

- Participants:
  - Individuals who had an adult onset hearing loss, and were gainfully employed participated (n=12)

- Data collection:
  - Audio–recorded semi–structured interviews
  - A photo elicitation interview technique was employed to generate the most relevant data (disclosure patterns in 5 typically occurring situations)

- Content analyses were used to extract pertinent information

Five themes influenced disclosure

- The importance of the situation
- Sense of control
- Community affiliation
- Burden of communication
- Coexisting issues related to hearing loss
“But it is hard, it is hard on the psyche [...] Most of these teleconferences I organize, so I’m not only a participant, I’m the chairperson. So if I don’t understand, then that’s even worse.”

• The importance of the situation
  ○ Perceived responsibility in the situation
  ○ Costs versus benefits of disclosing hearing loss in the situation
• Sense of control
  ○ Predictability of work related tasks
  ○ Balance of power between the worker with hearing loss and the co-worker
• Community affiliation
  ○ Community affiliation jeopardized because hearing loss not considered ‘normal’
  ○ Difficult to understand “partial” hearing loss

“Self preservation kind of kicks in. I want this job. I need this job. And I want that salary. I'll handle him or her, the boss. And once I get into the job, then I'll cross that line and explain. It's not a good idea, but I would do it from time to time if that situation warranted it.”

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“First of all, I equip myself before I pick up the phone to call a company. I’ve done my homework on a company. So I tend to be more in control of the conversation....”

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“If somebody takes me to see a problem..., and mouths the words fix it. ... I would say you know, “We’re going to fix that for free!” and you’d see a smile come on their face, .... (or) “We’re going to have to look at that....” (laughs). Which means I need to get out of here and do some thinking about it.”

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“It’s sort of like, you know, waving a flag in their face that you have a problem. You do want to be treated normally. You don’t want to be treated differently.”

[There is] the land of the hearing, and the land of the non-hearing. What I call no-man’s-land is in between. I feel like I am trapped there... "in" the world, but not "of" it.”

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- Burden of communication
  - Perception that co-workers forget about hearing loss
  - Perception that hearing loss is disruptive to natural flow of interactions
- Coexisting issues related to hearing loss
  - Issues that result in fluctuating levels of hearing ability
  - Adaptive technologies and other accommodations

“they called a big meeting, and they have absolutely no accommodation for me. How could you forget?”

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If there's someone that doesn't know about it, and it's come to a point where it's probably more than the average person asking, "What? Can you repeat that?" then I disclose it.

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"I just wish I had a thermometer on my head that showed people what it was like today. ...Hearing loss is a hidden disability and to have tinnitus is sort of like a double whammy."
“if you see someone in a wheelchair you won’t ask them to go up stairs. I want people to see my hearing aid and be clued in from the beginning.”

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Discussion/Interpretations

- Most respondents assessed if they could manage the situation without disclosing.
  - If ‘yes’, how?
  - If ‘no’, costs and benefits of disclosure?
- Disclosure influenced by characteristics of the workplace:
  - Presence of other workers who also have hearing loss
  - Organizational support – size of employer, nature of work.
- Disclosure is also influenced by public support –
  - accessibility legislation
  - extent to which guidelines are put into practice
Take home messages

- People with hearing loss may also be impacted by group-associated stigmas related to age, gender, race, socio-economic status or geographic location.
- Each individual is different; their experience and response to stigma and discrimination (i.e., vulnerability versus resilience)
- It is expected that individual differences will reflect broader social conditions

Future work

- Most older adults multiple conditions (HL, VL, UI and MI)
- Stigmas impede upon:
  - recognition, identification of conditions
- Stigmas serve as an obstacle to:
  - help-seeking, service provision, and adherence.
- Older adults are challenged not only by health-related stigma but also by group-associated prejudice and discrimination
- The role of multiple sources of stigma and discrimination in the adoption and use of ATDs merits investigation
References


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