

'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

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

Jones, 1984



## possessing a stigma can result in *self-stigma*

- individuals who possess stigmatizing traits may direct prejudicial attitudes inwards



Major & O'Brien, 2005

## 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.

Southall, K., Gagné, J.-P., & Jennings, M. B. (2010). Stigma: A negative and a positive influence on help-seeking for adults with acquired hearing loss. *International Journal of Audiology*, 49, 804-814.

## 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.”

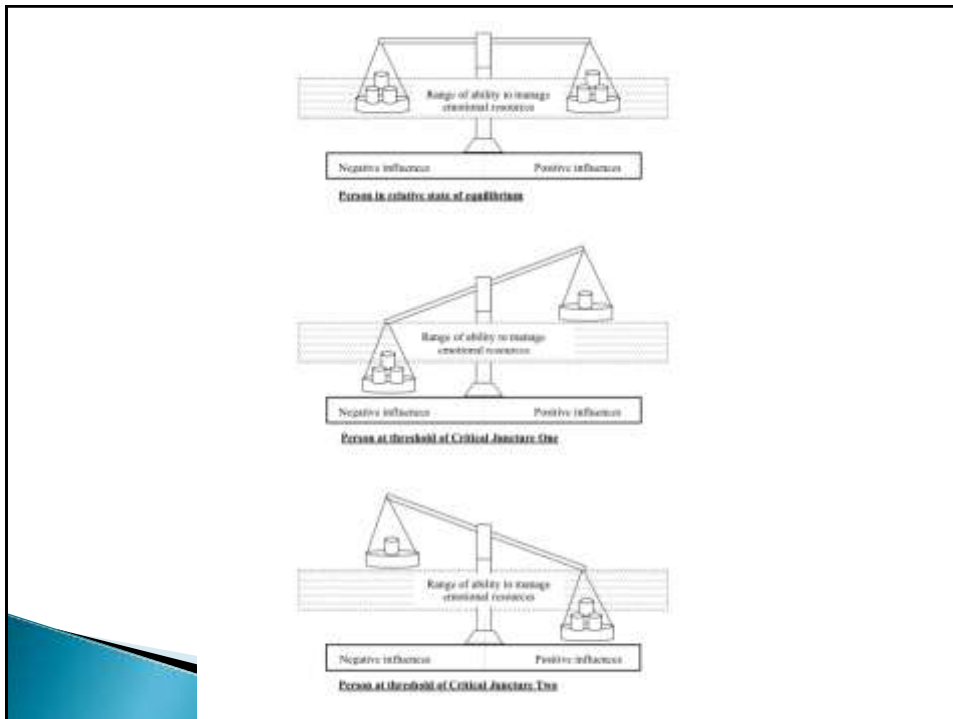
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“Every time someone (new) comes, ... All the emotions that I went through, ...is mirrored back to me. It almost makes what I went through worthwhile, because now there is a reason why it happened to me. Because now I'm having an impact on someone else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

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## 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
  - facilitators versus obstacles to disclosure
  - factors associated with these behaviours

Southall, K., Jennings, M. B. & Gagné, J.-P.  
 Factors that influence disclosure of hearing loss  
 in the workplace. *International Journal of  
 Audiology* EPub - Aug 3, 1-9 (2011).

## 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."*

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*"[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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## Five themes influenced disclosure

- 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.."*

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  - *Perception that co-workers forget about hearing loss*
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*“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.”*

- Burden of communication
  - *Perception that co-workers focus on 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*

## Discussion/Interpretations

- Most respondents assessed if they could manage the situation without disclosing.
  - If 'yes', how?
  - If 'no', costs and benefits of disclosing?
- 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

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