Stigma associated with hearing loss in older adults with hearing loss

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Acknowledgements

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Research project:
Stigma and disclosing (or not) one’s hearing loss in the workplace: The strategies used by people with hearing loss
Dedication

Our work in the area of stigma and hearing loss is very much inspired by the earlier work of our colleagues at the University of Montreal:

Dr. Raymond Hétu (deceased, 1995)
Ms. Louise Getty

Goal of Presentation

Describe the phenomenon of stigma and self-stigma related to hearing loss

Emphasize the importance of the stigma attached to hearing-impairment:
- As a barrier to audiological rehabilitation (AR)
- To propose avenues of rehabilitation that will make it possible to overcome the negative effects of the stigma associated with hearing loss
Stigma and Hearing Loss

Negative stereotypes and prejudices are attributed to people who have hearing loss.

They are perceived as:
- old
- cognitively diminished
- Poor/uninteresting communication partners

Kochkin (2000) noted that hearing loss is often misunderstood as an intellectual challenge or a deficiency in personality and character.
Marketrak Studies (Kochkin: 2000, 2007) indicate:

• Stigma is one of the main reason given by people to explain why they do not accept wearing hearing aids

• 40% of people with hearing loss who do not use hearing aids give stigma as one of the 5 main reasons for their decision
Marketrak Studies (Kochkin, 2000, 2007)

Reasons given by adults with hearing loss who were between 35 – 65 years of age, to justify non-adoption of hearing aids:

Do not admit hearing loss in public – 35%
Noticeable – 35%
Too embarrassed to wear – 34%
Makes you look disabled – 31%
Makes you look old – 31%

A glimpse of the image that people with hearing loss have of themselves (their own identity)
Stigma and Hearing Loss

Further reasons given by people with hearing loss to justify non-adoption of hearing aids (Kochkin, 2000, 2007):  

Too proud to wear – 29%
People treat you differently – 28%
Makes you look weak and feeble – 26%
People make fun of you – 22%
Makes you look mentally slow - 20%
Stigma and Self-stigma

A conceptual framework for understanding the effects and manifestations of self-stigma associated with hearing loss
What is Stigma?

It comes from Greek:

Originally, individuals who were stigmatized were people who had a physical trait or characteristic that was considered ‘deviant’ or ‘abnormal’ relative to a reference group (i.e., the outsider group) in a given society.

Devalued as individuals
They were discredited members of their society.
What is Stigma?

Stigma is:
A difference
A discredited attribute*
A sign of deviance from normality
Probably each one of us has felt discredited at a given time or in a given situation

It is likely that we have all experienced the effects of being stigmatized

*you do not have to be a child molester to be stigmatized...to feel stigmatized
Definition of Stigma

*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
Stigma: A Social Construction

A label attached by society; a phenomenon defined by society

‘society’ is defined from a sociological perspective, meaning: ‘a group of persons regarded as forming a single community’ or ‘any organized group of people joined together because of some interest in common’

• Personal attributes that are stigmatizing in one society may not be stigmatizing in another society (e.g., tattoos; body piercing)

• Stigmatizing traits may change as a function of many factors including time (e.g., use of tobacco, homosexuality)
Stigma: A Social Construction

Stigma is a social phenomenon that can be investigated from many different perspectives

- outsiders
- insiders
Stigma: Perspective of OUTSIDERS

Stigma may be studied from the vantage point of people who do not possess the stigmatizing trait (members of society in general)

These people are ‘outsiders’:

They are the people who hold prejudicial views; who stigmatize others

Outsiders report that people with hearing loss are old, senile, and socially unfit

Many outsiders avoid and/or ostracize individuals with stigmatizing conditions
Stigma: Perspective of INSIDERS

Stigma can be studied from the vantage point of those who possess a stigmatizing trait

Those people are ‘insiders’

Usually insiders are aware of the prejudicial views held by the outsiders

Often, insiders hold (consciously or not) the same prejudicial views about their stigmatizing condition as the outsiders

In the case of late-onset hearing impairment, outsiders become part of the insider group
Self-Stigma

Some *insiders* display *self-stigma*; these people agree with prejudicial views about their own stigmatizing trait.

*Self-stigma* brings about a *threat to one’s own identity* (*the way we perceive ourselves*).

*Self-stigma* often leads to higher levels of stress, shame, and lower self-esteem and self-efficacy.
Self-Stigma and maladaptive behaviors

To avoid situations of perceived identity threat, many people employ maladaptive coping strategies:

- **denial** (possible because HL is invisible)
- minimization
- normalization
- social isolation/withdrawal, avoidance, concealing the loss
Maladaptive Coping Strategies

Denial
The person insists that he/she is perfectly normal; that he/she does not have any problem hearing.

‘I hear very well; everyone mumbles these days.’
Maladaptive Coping Strategies

Minimizing the impact:

‘It’s not that bad!’
‘It doesn’t bother me!’
‘It does not stop me from living my life!’
‘I have some difficulties but I am not deaf!’
Maladaptive Coping Strategies

Normalization attempts:

‘It is normal when you have worked in noisy environments for 15 years!’

‘It is normal at my age!’

‘I am not worse than the others.’
Maladaptive Coping Strategies

Withdrawal/Isolation:

The person stops participating in social activities

The person prefers to stay alone, isolate himself/herself
Maladaptive Coping Strategies

Concealing:

Strategy used by some people who display self-stigma

Do not want to be identified as having the stigmatizing trait
Maladaptive Coping Strategies

Concealing:

Prevents individual from using appropriate communication strategies

Significant cognitive and emotional resources are expended in attempts to conceal hearing loss and the effects of hearing loss

Induces stress when (and to whom) to disclose vs. when (and to whom) to conceal

Self-stigma is an important obstacle to AR
Maladaptive Coping Strategies

To avoid being identified as a member of a stigmatized group, individuals might choose not to seek treatment or fail to comply with treatment regimens.

It is very likely that they will not agree to use amplification or any other type of assistive technology.
A Stigma-Induced Identity Threat Model

Major & O’Brien, 2005
Figure 3:
Conceptual framework displaying the elements of the Stigma-induced identity threat described by Major and O’Brien (2005)
Stigma-Induced Identity Threat

Responses to stigmatization depend on the person’s assessment of the demands of the situation.

A situation is assessed as stigmatising if:

• one appraises a situation as harmful (or potentially harmful) to his/her social identity and
• when the stress induced by the situation is judged to exceed the resources available to cope
Figure 3: Conceptual framework displaying the elements of the Stigma-induced identity threat described by Major and O’Brien (2005)
Stigma-Induced Identity Threat

Appraisals of one’s identity threat are determined by an interaction of the three constructs:

1. Collective Representations
   Shared understandings and beliefs about stigmatizing conditions
   Collective representations (society’s) and the stigmatized person’s own view of the stigmatized trait will determine whether or not their will be a perceived identity threat
Figure 3:
Conceptual framework displaying the elements of the Stigma-induced identity threat described by Major and O’Brien (2005)

A
Collective representations

B
Situational cues

C
Personal characteristics

D
Identity threat appraisals

E
Involuntary and voluntary responses to stress

F
Outcome
Stigma-Induced Identity Threat

Appraisals of one’s identity threat are determined by an interaction of the three constructs:

2. *Situational cues*

   Factors related to the physical and social environment in which a given activity takes place.
   
   It is the person’s perception of the situational cues that are important (real or not).
Figure 3:
Conceptual framework displaying the elements of the Stigma-induced identity threat described by Major and O’Brien (2005)
Stigma-Induced Identity Threat

Appraisals of one’s identity threat are determined by an interaction of the three constructs:

3. **Personal Characteristics**
   
   The personal attributes of the person such as age, gender, educational level, occupation, etc...
   
   Attitudes, beliefs, level of optimism
Figure 3:
Conceptual framework displaying the elements of the Stigma-induced identity threat described by Major and O’Brien (2005)

A
Collective representations

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Outcome
Stigma-Induced Identity Threat

Responses to stigmatization may be similar to responses that may occur in any stressful situation

Responses to identity threat can be:
  involuntary (e.g., emotional, physiologic)
  voluntary (e.g., behavioral, emotional)
Stigma-Induced Identity Threat

Coping strategies used to deal with stress caused by an identity threat are the same as the coping strategies one uses in response to any other stressful event.

Generic models of stress and coping may explain how individuals react when they perceive an identity threat due to a stigmatizing event.
Figure 3:
Conceptual framework displaying the elements of the Stigma-induced identity threat described by Major and O’Brien (2005)

A  Collective representations

B  Situational cues

C  Personal characteristics

D  Identity threat appraisals

E  Involuntary and voluntary responses to stress

F  Outcome
Stigma-Induced Identity Threat

The outcomes of coping responses may be:

- Attitudes (self-defeating, pessimistic)
- Feelings (self-esteem, shame, fear, no confidence)
- Behaviours (academic performance, job performance, isolation, health conditions)
Implications for and Application to AR

Types of intervention programs:

Interaction with others who have the same stigmatizing trait (*Normalization Process*)

Cognitive-Behavioural Therapy, Social Learning Theory & Perceived Self-efficacy
The Normalization Process

Hétu, 1996
The Process of Normalization

Group Communication intervention programs:

- Shares his/her life habits & experiences with others
- Develops communication strategies
- Shares its successes & failures with people living similar difficulties
- Develops an identity (a sense of belonging) to the group
- Reduces shame and deviance (normalization)
- Develops a new social identity
- Restores a positive self-image
Process of Stigmatization (Hétu, 1996)

Stigmatization Process

Hearing-impaired person

- Hearing difficulty
- Shame
- Guilt
- Dual identity

Unimpaired entourage

- Deviant behaviour
- Stigmatizing attitude/behaviour
- Withdrawal/isolation
- Concealing stress/anxiety
- Judgement of the deviance

Withdrawal/isolation

Concealing stress/anxiety

Dual identity

Stigmatizing attitude/behaviour

Judgement of the deviance
Process of Normalization (Hétu, 1996)

Normalisation Process - Step 1

- Hearing-impaired person
  - Hearing difficulty
  - Normal identity
  - Support
  - Ridding oneself of guilt

- Hearing-impaired peers
  - Normal behaviour
  - Hearing difficulty
  - Sharing the difficulties

- Participation
  - Sense of partnership
Process of Normalization (Hétu, 1996)

Diagram: Normalisation Process - Step II

- **Hearing-impaired person**
  - Hearing difficulty → Explicit limitation
  - Normal Identity
    - The limitation taken for granted
    - Accommodation depending on anticipated effort/benefits
    - Use of helping means
      - Requests for adjustments
      - Participation

- **Unimpaired entourage**
  - The difference acknowledged as such
The Process of Normalization

‘I am not the only person going through difficult, stressful, uncomfortable and shameful moments due to my HL.’

‘I am not crazy. It’s normal to feel and behave that way when one has a HL’

‘People with hearing loss are not necessarily old, uninteresting, unpleasant, etc… They just have difficulty understanding others in certain situations
'Despite my hearing loss, I too can be a normal and interesting person.'

'Strategies exist to reduce the number of communication breakdowns.'

'I can simply inform my communication partners that I have difficulty hearing and that it would be useful for me if they used communication strategies.'
The Process of Normalization

When the person’s self-image is restored, they are more receptive to intervention. They will:

- More easily accept using communication strategies
- More easily accept wearing hearing aids
- Have more positive experiences and successful communication; increase their self-confidence; be less likely to adopt aggressive behaviours or withdrawal

And

People around them will be more interested in communicating with them, which improves the self-image (a positive ‘vicious circle’).
Frameworks for Intervention

Cognitive-Behavioural Therapy
Social Learning Theory
Perceived Self-efficacy
Using a Perceived Self-efficacy Framework

Bandura, 1977; 1986; 1995
Jennings, 2005
Jennings & Gagné, 2008-09
PSE

PSE refers to, “beliefs in one’s capabilities to organize and execute the courses of action required to manage prospective situations. Efficacy beliefs influence how people think, feel, motivate themselves, and act.” (Bandura, 1995, p. 2)

Outcome Expectations refers to,
“beliefs that performing the behavior will result in the desired health outcome.” (Ireland & Arthur, 2006)
PSE

Major assumption, “unless people believe they can produce desired effects by their actions, they have little incentive to act.” (Bandura, 1998, p. 624)

To be competent, the individual requires both skills and SE beliefs to use the skills they have effectively
Processes that Regulate Human Functioning  Bandura, 1997

Cognitive Processes
   Individual must believe they have the skills needed to act

Motivational Processes
   Individual must be motivated to act

Affective Processes
   Individual must believe that they are in control and are not vulnerable

Selection Processes
   Individual must have the ability and believe that they can problem-solve, plan, and be adaptive
Summary

Self-Stigma is a barrier to AR

Understanding Stigma and Self-Stigma can assist us to develop AR programs to overcome the negative effects of the stigma associated with hearing loss:

- Interaction with others who have the same stigmatizing trait (Normalisation Process) (Hétu, 1996)

- Cognitive-Behavioural Therapy, Social Learning Theory & Perceived Self-efficacy (Jennings, 2005; Gagne, Southall, & Jennings, 2009)
Questions ...

Thank You!

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