# Stigma associated with hearing loss and ageism: An obstacle to AR

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#### **Outline of Presentation**

- 1. The concepts of social stigma, selfstigma, ageism and auto-ageism
- 2. Results of qualitative research project
- 3. Implications for rehabilitation







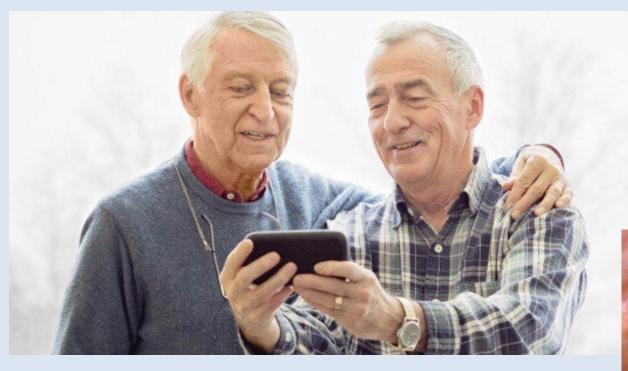


the possession of, or the belief that one possesses, some attribute or characteristic that conveys a social identity that is devalued in a particular social context.

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

Crocker, Major, and Steele (1998)

# Stigma: A Social Construction Can vary as function of society and time

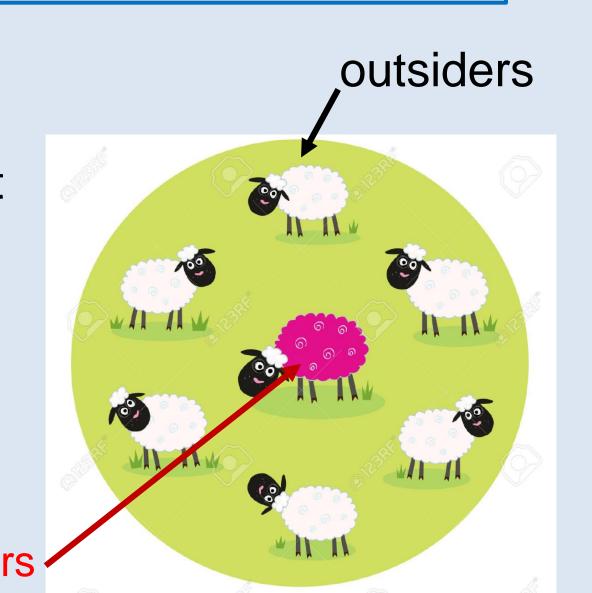






#### Stigma: A Social Construction

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



#### OUTSIDERS

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

Outsiders report that people with HL are old, senile, socially unfit, a burden to society

Outsiders tend to avoid and/or ostracize individuals with stigmatizing conditions

#### INSIDERS

Are aware of the prejudicial views held by the outsiders (obesity, unwed mothers, social welfare)

Some *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 may become part of the insider group

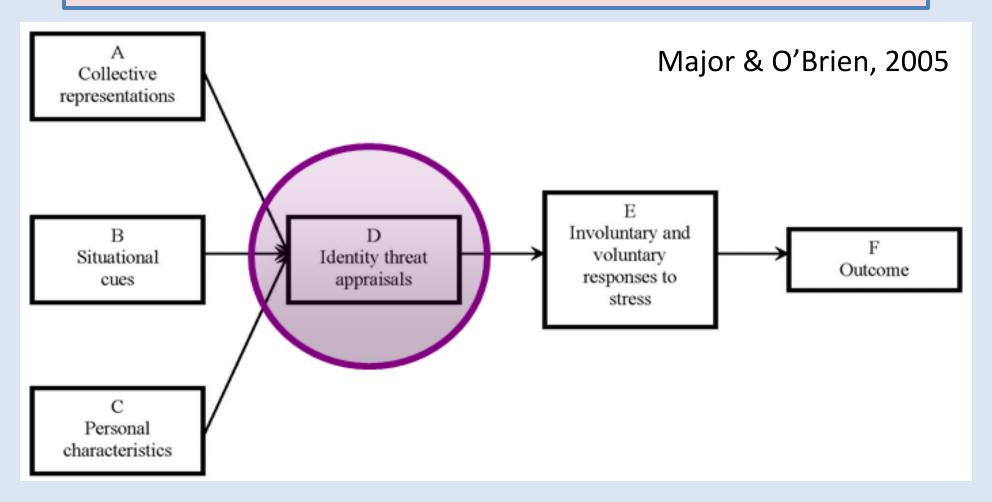
#### SELF-STIGMA

Some *insiders* display *self-stigma*; these people hold the same prejudicial views concerning their stigmatizing trait (people who are obesesome yes; some no)

Self-stigma brings about a threat to one's own identity (in the way we perceive ourselves)

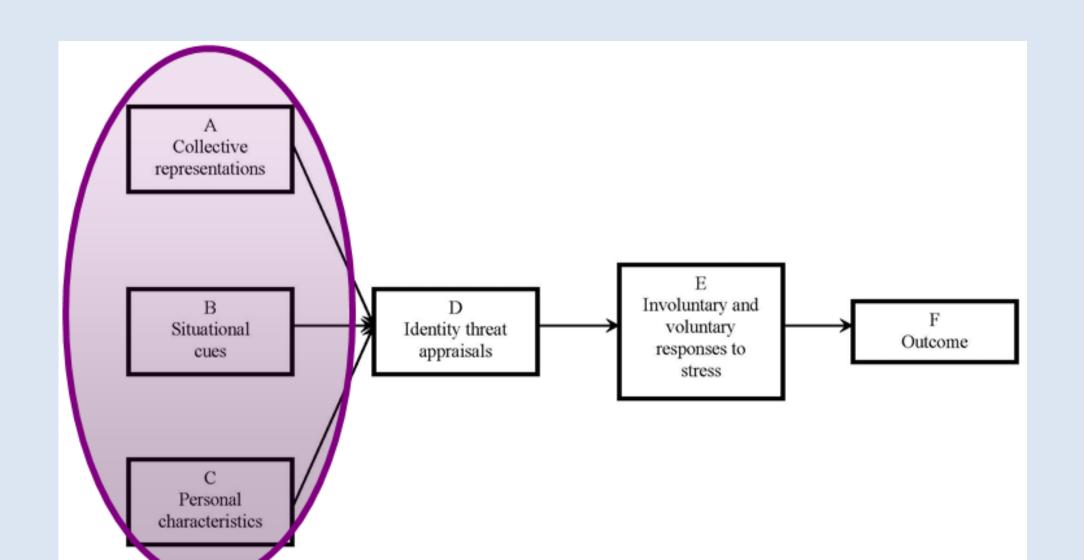
Self-stigma often leads to higher levels of stress, shame, and lower self-esteem and lower self-efficacy

#### A Stigma-Induced Identity Threat Model

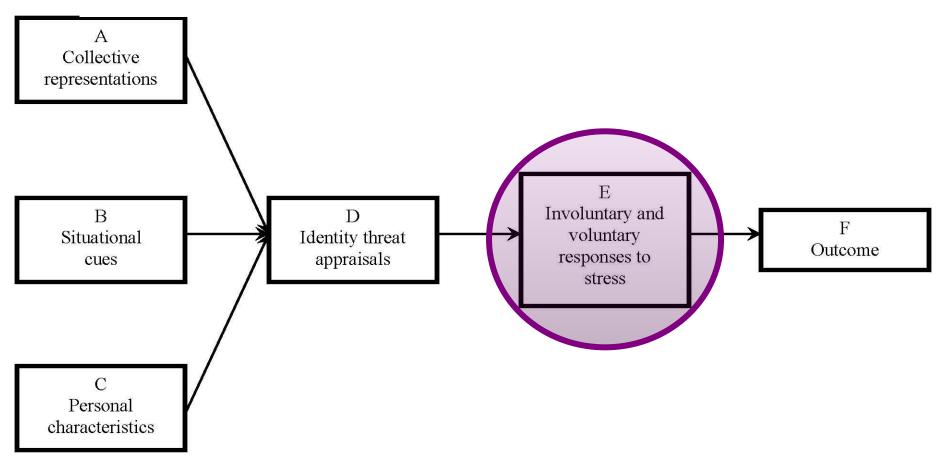


Self-stigma: Appraisal of a situation as harmful (or potentially harmful) to one's social identity

#### Factors that influence self-stigma



#### Stigma-Induced Identity Threat



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

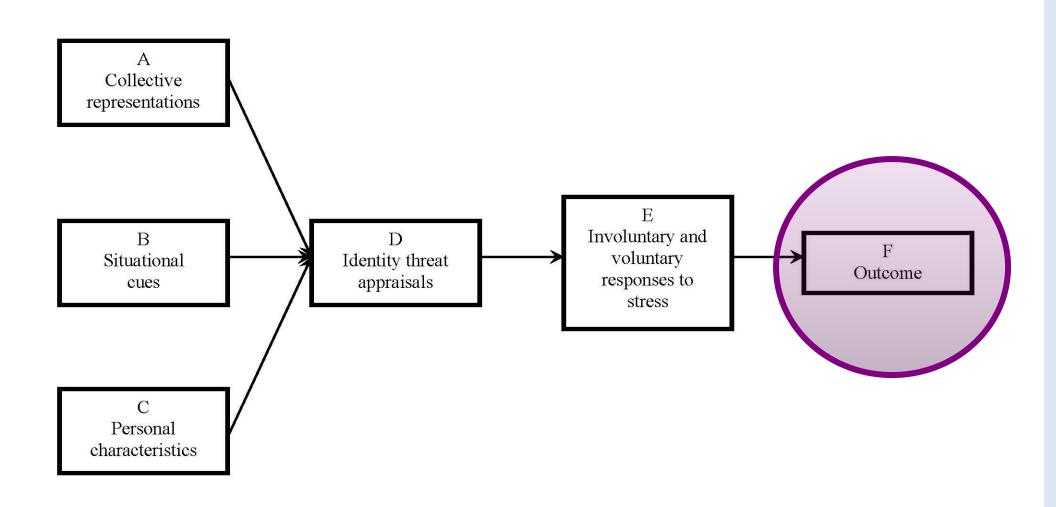
#### Symptoms of STRESS



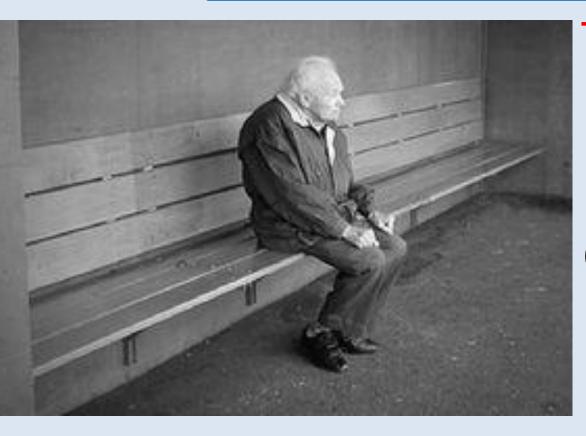
#### Stress Symptoms

Cognitive	Emotional	Physical	Behavioral
Memory problems	Moodiness	Aches and pains	Eating more or less
Inability to concentrate	Irritability or short temper	Diarrhea or constipation	Isolating oneself from others
Pessimistic approach or thoughts	Agitation, inability to relax	Increased frequency of urination	Procrastinating or neglecting responsibilities
Anxious or racing thoughts	Sense of loneliness, isolation	Changes in blood glucose	Using alcohol, cigarettes, or drugs to relax
Constant worrying	Feeling overwhelmed	Nausea, dizziness	Sleep disorders
Poor judgment	Depression, general unhappiness	Chest pain, rapid heartbeat	Nervous habits (e.g. nail biting, pacing)
		Indigestion	
		Loss of sex drive	
		Frequent colds	
		Irregular periods	I

#### Stigma-Induced Identity Threat



#### Stigma-Induced Identity Threat



The outcomes of coping Responses may be:

Attitudes and feelings
(self-defeating, pessimistic,
low self-esteem, shame,
fear, low confidence)

**Behaviors** (social isolation, poor performance at school/work, physical/mental health)

#### **AGEISM & AUTO-AGEISM**





#### **AGEISM & AUTO-AGEISM**

#### Ageism:

discrimination against people on the grounds of their age; Typically, discrimination against the elderly

#### Auto-ageism / Interiorized ageism:

older adults who hold the same negative/ discriminatory stereotypes (consciously or not) toward the elderly

the identity-threat model proposed by Major & O'Brien (2005) can be applied to auto-ageism

#### Our society's view of older adults

#### Ageist attitudes:

'slow' physically and cognitively not healthy (sick, chronic disability)

poor performance - efficiency burden (cost) to society dementia not interesting to interact with being a bother to others Loss of autonomy

Ageist comments that we (!) use:

'She did great for her age', 'looks great for her age' 'Still very active for a person of 77 years of age' 'elderspeak' (!)



# Research program on stigma associated to HL in older adults and Ageism (2012 – 2015)

- 1. Review of literature
- 2. Qualitative study
- 3.Development of rehabilitation program to counter self-stigma and self-ageism

#### Qualitative Research Project

To characterize the perceptions of self-stigma and auto-ageism

To incorporate relevant findings into the development of an intervention program



#### Methods

#### The Interviews:

Queries/conversations on four main topics and followup questions:

- Society's views of HL associated with aging
- Their own personal views of HL accompanying aging
- Society's view of the elderly (general)
- Their own personal view of aging



#### Methods

Experimental approach: qualitative & descriptive Participants (n=37)

All 37 interviews video recorded, and transcribed

In depth analyses of 19 interviews (sampling on

the basis of contrasting

cases)

Listened/read the
 remaining 18 interviews
 (with analysis when
 warranted)



#### Methods

#### Categories of participants recruited

- •All over 65 years of age (range between 65 89 yrs of age)
- Men & Women
- Rural & urban settings
- With HL & without a diagnosed HL
- •With HL: use & non use of hearing aids
- Significant others (no known HL)

#### Coding system

#### Seven (7) principal/main themes:

- Hearing Loss
- Aging
- Stigmatization
- Self-stigma of HL
- Ageism
- Auto-ageism
- Social identity

\*Several sub-themes for each main themes



#### Sub-themes associated with HL (7)

- Denial/minimizing effect of HL
- Becoming aware of HL
- Functional limitations due to HL
- Coping with problems caused by HL
- 'Models' of other persons with HL
- Impact of HL
- Use of hearing aids

## Sub-themes related to the AGING PROCESS

- The 'self' representation of aging
- Participant's aging trajectory
- Changes associated with aging
- Feeling of being useful
- Revealing one's age
- Feeling of accomplishment

#### Main findings

The effects of self-stigma associated with HL and auto-ageism are similar

- Perceived identity threat
- Social identity is 'diminished'
- Develop (and focus on) a negative self-image
- Try to conceal or normalize the stigmatizing trait
- Cost-benefit analysis of revealing/disclosing their stigmatizing trait
- Poor self-esteem; Poor self-efficacy
- Shame (as in not good for our self-pride)
- Social withdrawal

#### Main findings

- For some people having HL and aging does not seem to have a negative impact on their social identity (<u>not an identity threat</u>)
- Some participants <u>displayed self-stigma</u> and/or auto-ageism

#### When there is an identity threat

Individuals have a more rigid (unidimensional) perception of who they are (their social identity)

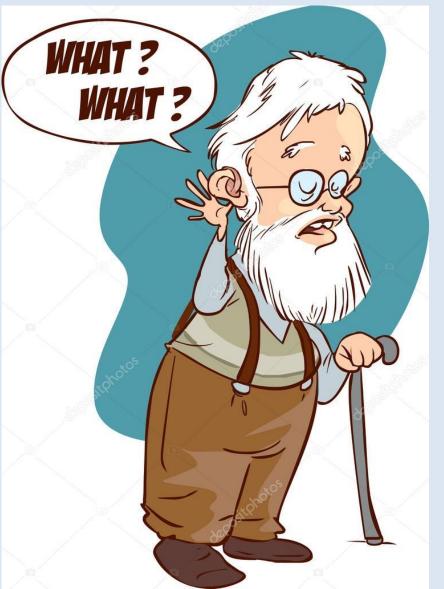
AMONG ALL THE COPONENTS USED TO GENERATE THE IMAGE OF ONE'S SELF, THE (SELF-) STIGMATIZING TRAITS, WHICH CREATE AN IDENTITY THREAT, ARE GIVEN A LOT OF WEIGHT

#### When the identity threat is minimal

Individuals have a more optimistic and flexible (multi-dimensional) perception of who they are as a person (their social identity)

**AMONG ALL THE COPONENTS USED TO** GENERATE THE IMAGE OF ONE'S SELF, THE **SELF-STIGMATIZING TRAIT IS NOT GIVEN TOO MUCH WEIGHT. OTHER (including new) POSITIVE TRAITS/ISSUES ARE GIVEN** PROPORTIONALLY MORE WEIGHT.. SO, THERE IS NO (MINIMAL) IDENTITY THREAT.

#### For some people who display self-



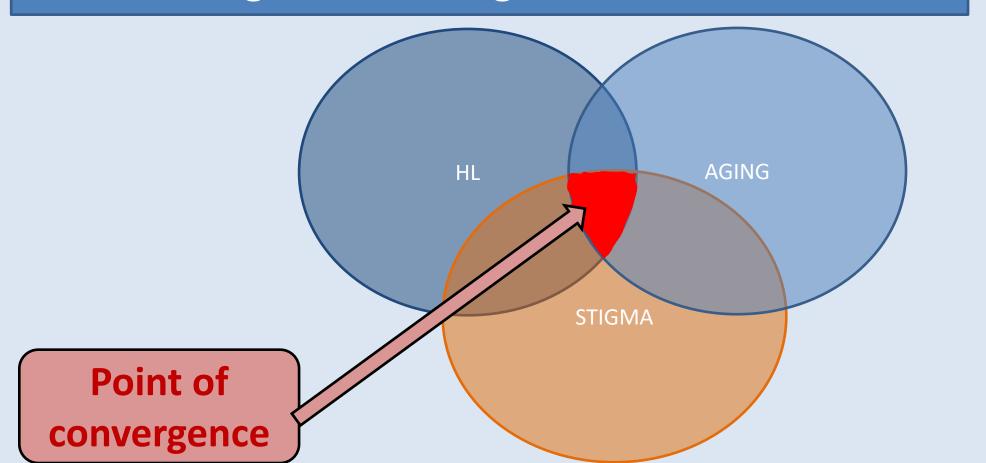
ageism, HL acts as a marker of aging



#### **SECONDARY ANALYSIS**

(verbatims that addressed HL and AGING)

The goal was to investigate the point of convergence among those the themes



#### Secondary analysis: Three categories of verbatims

- 1. A positive or neutral perception of HL associated with aging
- 2. HL is one of the numerous health conditions that is associated with aging; it is part of the 'normal' process of aging
- 3. HL is a (negative) marker of aging for oneself as well as for others

# Theme 1: A positive or neutral perception of HL associated with aging

### Theme 1: A positive or neutral perception of HL associated with aging

I: Why do you think that they don't want to admit they are getting older? They don't have much hair, they must realise that they are aging. Or, white hair, they wear glasses, they have false teeth, I don't know why, what's the difference?

# Theme 1: A positive or neutral perception of HL associated with aging

P: Me, I don't understand that. But, I realize that I am different from the others without knowing exactly why.

I : Because you adapt to situations?

P: There is no other way to live happy than to live with what we have, to see everything positively. It's the glass half-full all the time. Why crumble?

# Theme 1: A positive or neutral perception of HL associated with aging

I: There are some older people that will wait before they consult. They will wait before they use hearing aids because they don't want to look old.

P: Oh, no. That's not me. All that didn't bother me one bit.

I: But... what is the association? Really, is it true that we could look older if we wear hearing aids?

Continued....

# Theme 1: A positive or neutral perception of HL associated with aging

P: We... we look older. Miss, if we don't use them and we spend all our time not understanding and asking others to repeat.. Now, that's old.

[...]

P: But me, it is not a handicap.. On the contrary... Listen, life is more pleasant with them (referring to the HAs)

#### Theme 2:

HL is one of the numerous health conditions that is associated with aging; it is part of the 'normal' process of aging

I: Would you say that you accept well.. The fact that you have HL?

P : Oh yes.

I: Yes?

P: Well yes. When we get older we have to accept all sorts of things

1: Ok.

JLB: All sorts of disabilities (laugh..)

P: Well, my understanding is that our ears age like our skin ages, our eyes, our bones. It is like we age with all the illnesses that occur when we retire [...] And aging, it is part of the process of being alive. Are we going to turn against ourselves because we are getting older?

I: That's it, as you mentioned before, if I want to live a long-time, well I will age.

P: Well, I have to take care of myself in everything that can help me age better.

P: Because, I said, there... it is the aging process.

1 : Ok.

P: Like what I am presently doing about my weakness, and my balance problem. Good is good. It is the aging process. It's normal!

I: How did you react to HAs? That we suggested you use HAs?

[...]

P: How.. How I... very well!

I: Yes but, what about the image.. What kind of image is ...

P: No because, it is part of aging. It is part of aging sometimes.

I: There are people for whom using HAs is.. an extremely painful step. What's your understanding of that?

P: It's like everything that forces us to admit that we are old, you know.

I : Ok.

P: Well you can't sidestep it..

I: It is like a marker continued...

P: It's a marker.. You can't miss it you know. We put on our HAs... so he's deaf you know.

1 : Ok.

P: Well I don't want to be deaf, and I don't want to be old and I don't want to die. Let's say things very semantically... very clearly.. Bing.. Bang.. Bang..

P: So the first audiogram that I had done, the audiologist asked me: Do you want HAs? I said 'hell no'. I don't want any. I don't need them yet.

I : Ok.

P: «Come back in one or two years». (laugh)

Continued...

I: You said: «I don't want any?»

P: Well no!

I: Why don't we want them?

P: We don't want any because it is a synonym of being old!

P: Well, it is because I didn't want to.

I: You didn't want to?

P: (laugh)

I: Wait a minute there!

P: Well you know. The idea that many people have, it is even my thinking, when we have a HA it is because we are old.

# Sample of findings Wallhagen (2010)

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'...having the hearing aid is another thing, like my gray hair, that will identify me as an old person.'

"I guess, don't want to let on that I'm getting on in years as it were . . . the association of hearing aids with aging . . . . But the stigma is associated with the aging rather than anything else."

Sample of findings Wallhagen (2010)

I guess young people have near-sightedness. But hearing loss seems to be affiliated with aging . . . The fact of having a big hearing aid says, I don't care how you look otherwise, but you're old . . . . So, I like to think that I'm not old. But then the hearing part says "Wait a minute, you are old." I mean, especially if you wear something that says, "Hey guys, you know, I'm old! I'm an old man," . . . .

#### Conclusion

For certain persons using HAs is a marker of aging... of being old

The problem may not be the HL per se

We don't want HAs because it is associated with being old

We don't want others to think we are old

#### Conclusion

Implications for rehabilitation...

For those persons it may important to address self-ageism rather than the stigma associated specifically to HL

HL may be just one of the negative markers of aging. If so, addressing HL will not change the primary issue of self-ageism

# Intervention programs to counter self-stigma associated with HL and auto-ageism

#### Southall and Gagné (2016-2018)

Systematic review of treatment programs to overcome self-stigma

N ≈ 60 studies

- Mainly depression and mental health (also HIV-AIDS, weight loss, alcoholism, leprosy...)
- In person (individual or group); web-based
- Duration of programs varied widely (1 session to – several weekly meetings)
- Outcome measures: mainly quantitative; some qualitative

#### Overcoming Self-stigma

#### Intervention programs:

- Normalization process (Interact with others with the same stigmatizing trait (Hétu, 1996)
- Cognitive-Behavioural Therapy (CBT)
- Social Learning Theory & Perceived Self-Efficacy (PSE)
- Acceptance and Commitment Therapy (ACT)

#### Insights....

- Few RCTs...
- Hard to recruit participants (persons who deny, minimize their stigmatizing trait; especially when it is invisible!). One approach may be.. Train the trainer.
- Overcoming self-stigma is not a all or none situation.. It is a process.. Readiness for change (emotional, cognitive, behavioral)

#### Insights....

- For some (e.g., Corrigan) the ultimate outcome measure is outing/disclosure: Informing (or admitting to) others of your stigmatizing trait.
- Group treatment programs that incorporate the principles and techniques of self-efficacy (Bandura, 1977), namely: <u>mastery experiences, vicarious</u> <u>experiences, social persuasion, reduce</u> stress reactions

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Thank you for **Your Interest** and attention