Understanding the Stigma Associated with Hearing Loss in Older Adults

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Abstract

Stigma has been defined as "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). In most developed societies there is a stigma associated with hearing loss. Many people with hearing loss experience self-stigma. That is, not only are they aware of the prejudicial views held by others, but they themselves (consciously or not) hold similar views about people with hearing loss. Self-stigma constitutes a major obstacle to seeking rehabilitation services. The goal of this chapter is to describe the effects that stigma and self-stigma have on people with hearing loss. First, the general phenomenon of stigma and self-stigma are described. Then, a contemporary model of self-stigma (the Perceived identity threat model of self stigma; Major & O'Brien, 2005) is presented, and its application to hearing loss is provided. Finally, the applications of this perspective of stigma for the rehabilitation of older adults with hearing loss are discussed.

Understanding the Stigma Associated with Hearing Loss in Older Adults

In most developed societies there is a stigma associated with hearing loss. People with hearing loss often have negative stereotypes and prejudices attributed to them that result in a deleterious effect on how they are perceived by others. People with hearing loss are often perceived as senile (Oyer & Oyer, 1985), uninteresting (Heine & Browning, 2002; Hétu, 1996) and/or undesirable communication partners (Jones, Farina, Hastorf, Miller, & Scott, 1984). Studies on the hearing aid effect have repeatedly shown that people are rated more negatively by others if they are seen wearing a hearing aid (Blood, Blood, & Danhauer, 1977; Blood, 1997; Doggett, Stein, & Gans, 1998; Gagné, Stelmacovich, & Yovetich, 1991; Johnson, et al., 2005; Ryan, Johnson, Strange, & Yonovitz, 2006). However, stigma also has negative consequences on how many people with hearing loss perceive themselves. The goal of this chapter is to describe the effects that stigma have on people with hearing loss.

Stigma and Self-Stigma: Definitions

In ancient Greek societies, people who were judged to be "deviant" or "abnormal" relative to their countrymen were punished (Goffman, 1963). "Stigma" was the word Ancient Greeks used to designate the cuts and burns inflicted on deviant individuals. People who had these wounds were devalued as individuals and discred-

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ited as a member of their society. In modern times, any deviant trait or personal attribute (physical, behavioral, personality, psychological, etc.) that brings discredit to a person may be a source of stigma (Goffman, 1963). For example, in some societies attributes such as obesity, cognitive impairment, religious beliefs or some activities (such as hunting, riding motorcycles, smoking, etc.) may constitute a stigmatizing trait. Goffman (1963) suggested that stigma signifies marks that designate the bearer of a spoiled identity and that this person was less valued in society.

More recently still, stigma has been defined as "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). Based on this description, two characteristics of social stigma are worthy of discussion in relation to hearing loss. First, in many cases, it is possible for an individual to conceal the attribute that defines the stigma. Quinn (2006, p.84) defined a *concealable stigma* as, "a stigmatized identity that is not immediately knowable in a social interaction". While some stigmatizing traits such as skin color or physical deformity are not easily concealed, other traits such as hearing loss can be hidden. In many circumstances, individuals may choose to conceal (or not disclose) their acquired hearing loss from the people with whom they interact. Research has shown that, relative to conspicuous stigmatizing attributes, possessing inconspicuous stigmas have both advantages and disadvantages.

There are some benefits associated with concealing a stigmatizing trait from others. First, by keeping the stigma hidden, the individual avoids potentially stigmatizing situations. To a large extent, it is up to the individual to decide if, when and to whom they reveal the existence and nature of the stigmatizing trait. However, there are also some drawbacks associated with concealing a stigmatizing attribute. For example, there is a constant discomfort associated with the possibility of having the trait disclosed during a social interaction (Smart & Wegner, 2000). Studies have also shown that concealing a stigmatizing trait increases the cognitive load required to take part in social interactions (Lane & Wegner, 1995; Smart & Wegner, 1999; Smart & Wegner, 2000). In addition to exerting the cognitive effort normally required to participate in a social interaction, a person attempting to conceal a stigmatizing trait (e.g., a hearing loss) expends supplementary cognitive resources by attempting to avoid being identified as "hearing impaired".

A second issue that is noteworthy to this discussion is that stigma is a *social construct* (a label created and attached by society: Major & O'Brien, 2005). Within this context, the term "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" (McKechnie, 1976). Stigmatization occurs in social settings where two groups of people exist: the outsiders and the insiders (Link & Phelan, 2001; Link & Phelan, 2006; Oyserman & Swim, 2001). Stigma may be considered from an *"outsider's perspective"*; that is, from the vantage point of people who do not possess the stigmatizing trait (Gagné, Southall, & Jennings, 2009; Goffman, 1963; Heijnders & Van Der Meij, 2006; Major & O'Brien, 2005). *Outsiders* report that people with hearing loss are senile (Oyer & Oyer, 1985), socially unfit (Jones, et al., 1984), and uninteresting communication partners (Heine & Browning, 2002; Hétu, 1996). However, stigma may also be considered from the perspective of *"insiders"*; that is, from the vantage point of people who possess a stigmatizing trait (Green, Davis, Karshmer, Marsh, & Straight, 2005; Jacoby, 1994; Scambler, 2006; Scambler, Heijnders, & van Brakel, 2006). *Insiders* are aware of the prejudicial views held by outsiders, and understand that some people devalue their identity. This distinction between insiders and outsiders implies that individuals who acquire their stigmatizing attribute in adulthood (as is the case for many individuals with hearing loss) likely realize that they now possess a trait that they may once have stigmatized. Hétu (1996) observed that for some individuals it may be difficult to reconcile this dilemma: negative and stigmatizing perceptions about people with hearing loss differ from non-negative perceptions about themselves. These conflicting and self-deprecating views often lead to high levels of stress (Crocker, et al., 1998; Major & O'Brien, 2005; Steele, Spencer, & Aronson, 2002), poorer self-image and lower self-esteem and self-efficacy (Heine & Browning, 2002; Hétu, 1996).

The phenomenon of holding prejudicial views about one's own stigmatizing trait is known as self-stigma (Gagné, et al., 2009; Major & O'Brien, 2005). Self-stigma serves as a threat to one's own identity (Major & O'Brien, 2005) and is a major obstacle to health care. To avoid situations of perceived identity threat, many people who display self-stigma adopt (mal)adaptive coping strategies such as concealment, denial, avoidance, and social isolation (Hallberg & Carlsson, 1993; Hallberg & Barrenas, 1995; Hétu, Getty, & Waridel, 1994; Link,

Struening, Neese-Todd, Asmussen, & Phelan, 2001; Major & Schmader, 1998; Perlick, et al., 2001; Ritsher & Phelan, 2004; Steele, 1997). Moreover, to avoid being labelled by others as someone with a stigmatizing trait, individuals with high levels of self-stigma might also refuse to seek rehabilitation services, because this act would disclose the fact that they have a stigmatizing trait. For example, a person with hearing loss may refuse to use hearing aids because that would divulge their hearing loss, and in turn that would trigger identity threats. Similarly, even though they are known to be effective, many individuals with hearing loss will not request the use of communication strategies (e.g., reducing the ambient noise level, requesting visual-speech cues, the use of clear speech) because doing so would divulge to their interlocutor that they have a hearing loss. Although these (mal)adaptive strategies may be successful in reducing the level of self-stigma, they might also lead to an increase in communication breakdowns, and to the development of self deprecating behaviors that lead to stress, withdrawal, isolation, loneliness and even depression.

In recent years, there have been significant breakthroughs in understanding how a social stigma may be perceived and experienced from the perspective of the *insiders (i.e.,* persons being stigmatized). In the next section, we describe one contemporary model of self-

stigma. In our view, most of the concepts described in the model are applicable to the social stigma associated with hearing loss, and to the way that people with hearing loss feel and behave when their self-image is diminished because of the social stigma associated with their impairment. Moreover, we believe that hearing health care professionals will benefit from having a better understanding of the self-stigmatizing process and its effects on people who have a hearing loss. Furthermore, integrating aspects of this model into the domain of audiologic rehabilitation will serve to complement and extend the current level of knowledge concerning stigma. Undoubtedly, a more comprehensive understanding of the self-stigmatizing process will lead to the development of more appropriate rehabilitation services for people who experience self-stigma due to their hearing loss.

A Perceived Identity Threat Model of Self-Stigma

Major and her colleagues have proposed a model of stigma that is based on two premises. The first premise of this model is that stigma puts a person at risk of experiencing threats to his or her social identity (Crocker, et al., 1998; Major & O'Brien, 2005; Steele, et al., 2002). The second premise is that having one's social identity deval-
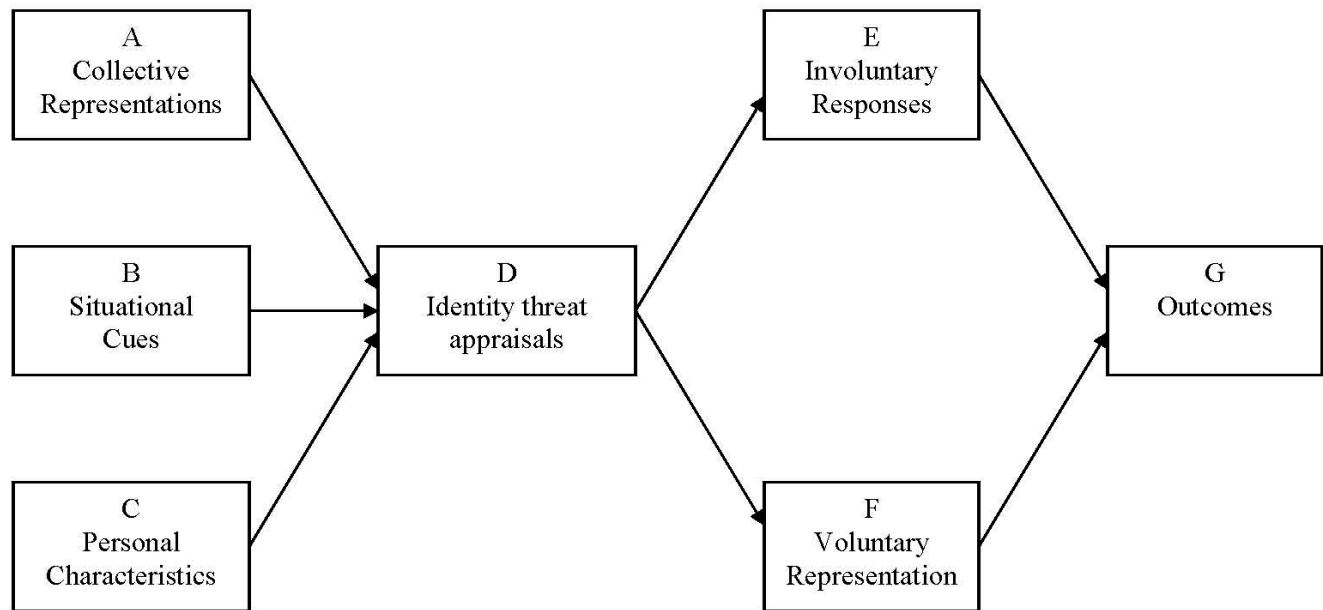
Figure 1. Conceptual framework displaying the elements of the Stigma-induced identity threat model described by Major and O'Brien, 2005. (Reproduced with permission).

ued leads to potentially stressful situations. Furthermore, according to this perspective, responses to stigmatization are similar to responses to stress. A diagram of the stigma-induced identity threat model proposed by Major and O'Brien (2005) is presented in Figure 1. An event is deemed to be potentially stigmatizing (see box D) when an individual appraises the demands imposed by a stigma-relevant stressor as potentially harmful to his or her social identity, and when the stress induced by the situation is judged to exceed the resources available to cope with those demands. Appraisals of identity threat (box D) are determined by the interaction of three constructs: collective representations (box A), situational cues (box B), and personal characteristics (box C). Responses to identity threats may be involuntary (e.g., coping responses in the emotional, physiological, behavioral and cognitive domains: box E) or voluntary (e.g., coping responses primarily in the behavioral and emotional domains; box E). A variety of outcomes may emerge from coping responses (box F), including attitudes, (e.g., self-defeating, pessimistic), feelings (e.g., self-esteem, shame, fear, lack of confidence) or behaviors (e.g., academic achievement, job related performance, communicative abilities, health). Although it is not illustrated in the diagram, this model is recursive, as the responses to an identity threat (box E) likely feedback to first level boxes A, B, and C, and to the second level box D. These feedback processes may attenuate or exacerbate the effects of stigmatization.

The following sections briefly describe the components of the stigma-induced identity threat model, and the process of self-stigmatization. A more thorough discussion of how this model may apply to understanding stigma in people with hearing loss has been described elsewhere (Gagné, et al., 2009; Southall, Gagné, & Jennings, in press).

Collective Representations

Collective representations are the shared (societal) understandings and beliefs about stigmatizing conditions (Crocker, 1999). Based on prior experiences, as well as exposure to the dominant culture, members of stigmatized groups develop shared understandings of their status in society. These collective representations include an awareness that they are devalued in the eyes of others, knowledge of the negative stereotypes held by the dominant society (the *outsiders*) concerning their stigmatizing attribute, and the knowledge that they could be victims and targets of discrimination (Crocker

et al, 1998). For example, in North America, most older adults with hearing loss are aware that they are judged by some to be cognitively diminished. Collective representations such as this influence how the stigmatized individual perceives and appraises stigma-relevant situations. According to the model, the strength or intensity of the collective representations held by society, as well as the stigmatized person's own view of the stigmatizing trait contribute to whether or not the person perceives an identity threat.

Situational Cues

Situational cues are factors that are related to the physical and social environment in which a given activity takes place. Individuals may experience a different level of identity threat in two different situations (Steele & Aronson, 1995). For example, Hétu (1996) reported that some blue-collar workers with hearing loss did not perceive that their identity was threatened when they were at home with family members. However, these same men did not want to use their hearing aids in the lunchroom at work, because in that situation, disclosing their hearing loss to others (or reminding others of the hearing loss) resulted in a high level of identity threat. It should be noted that an individual's perception of a situation does not always correspond to the reality of that situation. One's 'perception' of the level of threat associated with a given situation is more important than the actual objective level of threat present in that situation. Steele et al. (2002) reported that identity threats may be modulated as a function of the perceived situation in which the threat is appraised.

Personal Characteristics

The personal attributes of an individual may also modulate identity threat appraisals. These may include (but are not restricted to) age, gender, the level of manifestation of the stigmatizing trait (e.g., the number, and the severity, of activity limitations and participation restrictions attributable to a sensory impairment), educational level, occupation, aptitudes, attitudes, motivation, confidence level, level of optimism/pessimism and locus of control. An important factor that has been shown to influence the strength or intensity of identity threats is the extent to which the individual identifies with his or her stigmatized identity (Major, 2006). This phenomenon has been described as the 'level of stigma-consciousness' (Pinel, 1999). A person who holds a very

strong prejudicial view of a given stigmatizing trait will display a high level of stigma consciousness for that trait. Level of stigma consciousness influences the intensity of identity threat an individual perceives in a given situation. For example, while one person with hearing loss may perceive a high level of identity threat in a given situation, another person (with a similar hearing loss) may not perceive an identity threat at all. The difference between the two individuals may be attributable to their level of stigma consciousness concerning hearing loss. That is, the first person may (consciously or not) endorse prejudicial views concerning hearing loss, while the second person may not view hearing loss to be a stigmatizing trait. Two other personal characteristics that have been shown to influence perceived level of identity threat are: self-esteem and self-efficacy (Corrigan & Watson, 2002; Corrigan, Watson, & Barr, 2006).

Identity Threat Appraisal

Identity threat appraisals are judgments made by the stigmatized person concerning a potentially stressful event. The person evaluates if the present threat is relevant to personal goals or values, and determines if he or she has the necessary resources to cope with this situation (Lazarus & Folkman, 1984). Stigma-induced identity threats occur when an individual appraises the demands imposed by a stigma-relevant stressor as potentially harmful to his or her social identity, and as exceeding his or her resources to cope with the demands. The appraisal process can be automatic, nonverbal, instantaneous, and occur outside of consciousness (Smith, 1991).

Responses to an Identity Threat

One assumption of the proposed stigma-induced identity threat model is that experiencing a situation in which one's social identity is devalued is stressful. According to Major and O'Brien (2005), the stress created by a stigma-induced identity threat has the same characteristics as the stress created by any other non-stigma specific situation. Moreover, the authors claim that the coping strategies used by an individual to deal with stress created by an identity threat, will be the same as the coping strategies used by an individual in response to any other stressful event (i.e., not related to self-stigma). Accordingly, Major and O'Brien (2005) claim that generic transactional models of stress and coping (Lazarus & Folkman, 1984; Smith, 1991) may be used to explain how individuals respond when they perceive an identity threat due to a stigmatizing event.

The concept of coping is central to contemporary perspectives on stigma. In contrast to traditional views, contemporary perspectives portray individuals who experience stigmatization not as passive victims, but as active agents attempting to make sense of their world by preserving their self-esteem (Major, 2006). Stress related responses and coping mechanisms that arise following an appraised identity threat may be *involuntary or voluntary* (Major & O'Brien, 2005). An individual's involuntary responses to identity threats may include (but are not limited to) anxiety arousal, increased blood pressure, increase heart rate, increased (and shallower) breathing rate, and sweating. An individual's voluntary responses may include (but are not limited to) problem-solving, emotional regulation, avoidance and denial. Not unlike any other stressful event, an individual's stress response due to an appraised identity threat can consume valuable resources. An account of how stress and coping strategies may manifest themselves in relation to stigma associated with hearing loss was addressed by Gagné, Southall, and Jennings (2009).

Outcomes of Stigmatization

As mentioned in the previous section, coping strategies are used in response to the stress brought on by an identity threat. The goal of using coping strategies is to return the body, emotions, and behaviors to a state of equilibrium. The extent to which this goal is achieved varies according to the effectiveness of the selected coping strategies (i.e., some coping strategies may be successful while others less so).

The outcomes of coping responses may arise at different levels, including physiological, psychological, emotional, and behavioral. Moreover, one coping strategy may have several outcomes at different levels. For example, in an attempt to conceal one's hearing loss, an individual may occupy all the conversational space thus, thereby not allowing others the opportunity to express themselves. This strategy may be successful in relieving the potential stress of inadvertently disclosing one's hearing loss. However, it may also have a negative consequence, in that potential communication partners may shun the person with hearing loss because their social interactions with that person are not satisfying.

As mentioned in a previous section, although they are not displayed in Figure 1, there exists feedback loops at every level of the Perceived identity threat

model (Major & O'Brien (2005). For example, the coping strategies used in a given situation may have an effect on collective representations (e.g., the reactions of others involved in that situation) and personal characteristics (e.g., changing one's attitude, positively or negatively, concerning identity threat in that situation). Depending on the outcomes of a given coping strategy, the feedback may be positive (a successful approach to dealing with the identity threat and the stress), negative or neutral. Because of these feedback mechanisms, it is likely that over time the effect of using a given coping strategy will influence the level of subsequent identity threats perceived in a given situation. Thereby, feedback mechanisms will also alter the level of identity threat required to trigger a coping response. In evaluating outcomes, it is important to consider both the short-term and long-term consequences of using various strategies. Some coping strategies may result in positive short-term outcomes, but be appraised negatively when considered from a long-term perspective.

Applications for Rehabilitation

To our knowledge, in audiologic rehabilitation, presently there is no intervention program designed specifically to address self-stigma in people with hearing loss. However, such programs exist in other domains of health, most notably in the area of mental illness (Bergart, 2003; Corrigan, Kerr, & Knudsen, 2005; Klein, Karchner, & O'Connell, 2002; Penn, Kommana, Mansfield, & Link, 1999; Pinfold, Thornicroft, Huxley, & Farmer, 2005; Sirey, Bruce, & Alexopoulos, 2005). Like hearing loss, there is a stigma associated with mental illness that results in identity threats (self-stigma) in certain situations. Moreover, because mental illness is not characterized by any obvious physical trait (it is invisible), there are remarkable similarities in the ways that self-stigma is experienced among people who have mental illness, when compared with the experiences of those who have hearing loss. For example, many people with mental illness choose to conceal their condition from others (Quinn, 2006; Quinn, Kahng, & Crocker, 2004; Smart & Wegner, 2000). Also, it is common for people with mental illness to use maladaptive strategies (e.g., withdrawal and social isolation) to cope with perceived identity threats. Furthermore, as with people with hearing loss, many people with mental illness do not seek health services, or do not comply with their recommended treatments (Corrigan, 2004; Tsang, Fung, & Corrigan, 2006).

In the field of mental health there have been several attempts to develop intervention programs to overcome the deleterious effects of self-stigma (Borras, et al., 2009; Corrigan, et al., 2005; Corrigan, 2002; Crisp, Cowan, & Hart, 2004; Garske & McReynolds, 2005; Heijnders & Van Der Meij, 2006; Link, Struening, Neese-Todd, Asmussen, & Phelan, 2002; Pinfold, et al., 2005). Considering that the general experience and manifestations of self-stigma are similar in people with hearing loss and those with mental health problems (Van Brakel, 2006), it may be of interest to consider how intervention programs developed in the area of mental health may be adapted for people with an acquired hearing loss who exhibit high levels of self-stigma. A review of the literature reveals that, in the domain of mental health, self-stigma intervention programs typically incorporate: information on the targeted health condition and the deleterious effects of stigma and self-stigma; components of cognitive therapy; and, interactions with people who have the same health condition, most notably those who have successfully overcome self-stigma (Birbeck, 2006; Heijnders & Van Der Meij, 2006; Link, et al., 2002; Sartorius, 2006; Scambler, et al., 2006; Weiss, Ramakrishna, & Somma, 2006). Studies designed to evaluate the efficacy of self-stigma programs show that people who participate in those programs display increased self-esteem and self-efficacy (Watson, Corrigan, Larson, & Sells, 2007), as well as an increase in active coping skills (Borras, et al., 2009; Lecomte, et al., 1999). Moreover, the participants are more likely to seek health services and/or to comply with their recommended intervention program (Link, et al., 2002; MacInnes & Lewis, 2008). These findings are encouraging and provide insights on a conceptual approach as well as the content and the type of activities that may be incorporated into programs designed to address the issue of self-stigma associated with hearing loss.

Considering the above, it is possible (even likely) that group intervention programs designed to increase the levels of perceived self-efficacy (PSE: Bandura, 1977) among participants may be appropriate for people with hearing loss who display high-levels of self-stigma. The concept of PSE stems from Social Cognitive Theory (Bandura, 1995), for which the goal is to reconcile "knowledge" and "action". 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). PSE has three parameters: magnitude (an individual's rating of the relative level of diffi-

culty of an activity); strength (the degree to which individuals believe they can succeed in an activity), and generality (the degree to which PSE transfers from one activity to another). It has been recommended that health care promotion programs include a self-efficacy training component, wherein increases in *self-efficacy* have been shown to precede the adoption and maintenance of health promoting behaviours (Bandura, 1995; Redland & Stuifbergen, 1993).

The underlying assumptions of PSE are that: 1) people need to have a basic understanding of their predicament, and know that other people with the same health condition experience similar activity limitations and participation restrictions, 2) people need to know that strategies and assistive technologies exist, and that they are effective for overcoming the difficulties encountered, 3) people need to know how to use/apply these strategies, 4) people need to convince themselves that they can use these strategies, and, if they do use them they will have beneficial outcomes. Activities incorporated into *PSE* programs are designed to address these different issues. Furthermore, stress reduction techniques (relaxation exercises) are incorporated into intervention programs.

PSE training has been successfully incorporated into treatment programs in many disciplines including: counselling psychology (Smith & Nye, 1989), education (Ferrari & Parker, 1992), occupational therapy (Chen, Neufeld, Feely, & Skinner, 1999; Gage, Noh, Polatajko, & Kaspar, 1994; Gage & Polatajko, 1994; Passmore, 2004), nursing and medicine (Jenkins & Gortner, 1998; Resnick, 2001; Resnick & Jenkins, 2000; Resnick & Nahm, 2001; Resnick, Zimmerman, Orwig, Furstenberg, & Magaziner, 2001). Jennings (2005; 2009) incorporated a PSE training component in an audiologic rehabilitation program designed for older adults with hearing loss. Specifically, she evaluated the efficacy of a training program that included information on hearing loss, assistive technologies, communication strategies and incorporated *self-efficacy building components*. The people who participated in that investigation displayed improvements in strategy use, daily use of hearing aids and assistive device ownership. More recently, Jennings and Gagné (unpublished data) compared the efficacy of two intervention programs for older adults with hearing loss. One of the programs was based on the results of the previous study conducted by Jennings. The results of the study confirmed that older adults who participated in a PSE based training program showed significant improvement in overcoming their activity limitations and participation restrictions. Also, the level of *self-efficacy* of many participants improved. Upon reflection, this latter finding should not have been unexpected. Many of the elements of Jennings' program were similar to those typically used in self-stigma intervention programs.

In summary, there is evidence (mostly in the domain of mental health) that some intervention programs can efficaciously address issues related to self-stigma. Many components of a PSE based intervention program developed by Jennings and her collaborators (Jennings, 2005, 2009; Jennings & Gagné, personal communication, 2010) include activities that are consistent with the goals and structure of self-stigma programs used in other health disciplines. The studies conducted by Jennings et al., were not designed specifically to reduce self-stigma, and thus the outcome measures used in those studies do not make it possible to evaluate the efficacy of the intervention in reducing self-stigma. Nonetheless, the studies conducted by our team members (Jennings, 2005; Jennings, et al., 2009) were promising, in that some participants in those studies have reported improvements in self-esteem and self-efficacy after completing the intervention program. Further research is warranted to establish formally whether components of a PSE based program would be efficacious in overcoming the effects of self-stigma.

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