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# La stigmatisation reliée à la déficience auditive

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# La stigmatisation reliée à la déficience auditive

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# Résumé

Certaines personnes peuvent être stigmatisées quand elles présentent un attribut relié à une identité sociale qui est dénigrée dans un contexte particulier. Il existe plusieurs stéréotypes au sujet des personnes qui ont une perte d'audition. Le grand public associe souvent la perte d'audition à des comportements indésirables, au vieillissement et à une capacité intellectuelle réduite. Ces stéréotypes affectent négativement la participation des personnes ayant une perte auditive à diverses activités. Malgré les impacts évidents et importants que la stigmatisation a sur la participation sociale des personnes ayant une perte auditive et leur propension à recourir aux services de réadaptation, on constate une pénurie relative de recherche sur le stigmate lié à la perte d'audition.

Ces dernières années, les chercheurs en sciences sociales ont fait de grands pas pour conceptualiser le stigmate selon la perspective des personnes qui sont la cible des attitudes nuisibles. La plupart de ces concepts peuvent s'appliquer au stigmate social lié à la perte d'audition. Le premier article de cette thèse tente de placer le stigmate lié à la perte d'audition dans un modèle de menace à l'identité induite par le stigmate (stigma-induced identity threat model). Ce chapitre explore comment les services pourraient être modifiés pour mieux soutenir les individus qui montrent des signes que leur identité personnelle est compromise à cause de leur perte d'audition. De façon générale, les buts de ce manuscrit sont a) de dresser un bref résumé de la question du stigmate lié à la perte d'audition ; b) de présenter un modèle spécifique de menace d'identité induite par le stigmate et d'incorporer des notions propres au stigmate lié à la perte d'audition à cette conceptualisation générale du stigmate et c) de réfléchir sur la pertinence de ce modèle pour la réadaptation audiologique.

L'intention de la deuxième étude est de mieux comprendre comment le stigmate affecte les comportements de recherche d'aide des adultes ayant une perte d'audition acquise. Dix personnes ayant une perte d'audition, et appartenant à des groupes de soutien par les pairs ont participé à des entrevues semi-structurées audio-enregistrées. Les transcriptions de ces entrevues ont été analysées au moyen d’analyses thématiques. Les analyses ont indiqué que les répondants montre une plus grande propension à chercher de l'aide à la suite d’étapes charnières, où l’équilibre entre le stress négatif et l'énergie positive était rompu : a) un moment où le stress était de loin supérieur à l'énergie positive (première étape charnière) et b) un moment où l'énergie positive était de loin supérieure au stress négatif (deuxième étape charnière). On propose une série de représentations graphiques qui dépeignent comment les influences positives et négatives présentes dans l'environnement social et physique du répondant influencent la recherche d'aide.

Le but de la troisième étude est d'identifier les facteurs qui amènent des individus à cacher ou révéler leur perte d'audition dans leur lieu de travail. Des entrevues semi-structurées ont été menées en utilisant une technique d’élicitation par photographies pour susciter des informations liées à la révélation de la perte d'audition. Les thèmes dégagés des entrevues incluent : l'importance perçue de la situation, la perception du sentiment de contrôle, l'affiliation à la communauté, le fardeau de communication et la présence de problèmes connexes à la perte d'audition. Les résultats de cette étude offrent un aperçu du monde caché des travailleurs ayant une perte d'audition. Cette étude sert à documenter certaines stratégies que les travailleurs avec une perte d'audition utilisent pour contrôler leur identité professionnelle et, plus spécifiquement, comment certains gèrent le dévoilement de leur perte d'audition dans leur lieu de travail. Les résultats fournissent des informations utiles pour le développement de programmes d'intervention appropriés pour des travailleurs ayant une perte d'audition.

**Mots-clés** : déficience auditive acquise, stigmatisation, menace à l’identité induite par le stigmate, stéréotypes, préjudices, discrimination, travail, dissimulation, dévoilement, recherche qualitative, élicitation par photographies.

# Abstract

Individuals are stigmatized when they possess, or are thought to possess, an attribute or characteristic that conveys a social identity that is devalued in a particular social context. There are several stereotypes, or commonly held (often erroneous) beliefs about people who have hearing loss. The general public often associate people with hearing loss to undesirable behaviours, ageing, and reduced intellect. Stereotypes such as these negatively impact upon activities of daily living engaged in by people with hearing loss. In spite of the obvious and important impacts that stigma has on social participation and inclination to use rehabilitative strategies, there has been a relative dearth of research on the stigma associated with hearing loss.

In recent years, researchers in the social sciences have made great strides to conceptualize "stigma" from the perspective of people who are the target of prejudicial attitudes. Most of these concepts are applicable to the social stigma associated with hearing loss. The first study presented in this dissertation attempts to position hearing loss stigma within a model of stigma-induced identity threat. Overall, the goals of this paper are to a) offer a brief summary of hearing loss stigma; b) present a specific stigma identity threat model and incorporate ideas about hearing loss stigma into this general conceptualization of stigma; and c) reflect on the appropriateness of this model for the domain of rehabilitative audiology.

The intent of the second study was to better understand how stigma impacted upon the help-seeking activities of adults with an acquired hearing loss. Ten people who had hearing loss, and were members of peer-support groups participated in audio-recorded semi-structured interviews. Thematic analyses of verbatim transcripts revealed that respondents experienced a heightened propensity to seek help following Critical Junctures, when negative stress and positive energy were out of balance: 1) a time when negative stress far outweighed positive energy (i.e., C*ritical Juncture One)*; and 2) a time when positive energy far outweighed negative stress (i.e., C*ritical juncture Two*). A series of graphic representations are proposed that depict how positive and negative influences found in the respondent's social and physical environment influenced help seeking.

The purpose of the third study was to identify the factors that lead individuals to conceal or disclose their hearing loss in the workplace. We conducted semi-structured interviews using a photo-elicitation technique to aid in probing issues related to disclosure of hearing loss. Emergent themes included: Perceived importance of the situation, Perceived sense of control, Community affiliation, Burden of Communication and Coexisting issues related to hearing loss. This study serves to document some of the ways that workers with hearing loss manage their workplace identity, and more specifically, how some people manage revealing their hearing loss in workplace settings. The findings also inform the development of pertinent intervention programs for workers with hearing loss.

**Keywords** : hearing loss, acquired hearing loss, stigma, stigmatization, stigma-induced identity threat, stereotypes, prejudice, discrimination, help seeking, peer-support, work, workplace, concealment, disclosure, qualitative research, qualitative description, photo elicitation

# Table of contents

List of tables

# List of figures

*To Dad Southall and Mom Southall.*

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# Introduction

The purpose of this dissertation is to characterize and better understand how people with acquired hearing loss adapt to and manage this chronic disability in light of challenges presented by social and self-stigma[1]. Over the past fifty years, there have been noteworthy changes in the way social psychologists view the stigmatization process (Dovidio, Major, & Crocker, 2000). While it was once assumed that people who stigmatize others suffered from innate or subconscious turmoil, it is now thought that stigmatization is an unfortunate albeit natural result of normal cognitive processes and interpretation of social experience. Similarly, the understanding of people who are stigmatized has evolved. Social scientists once believed that possessing a stigmatizing trait invariably led to a range of negative consequences. However, current thinking suggests that people who are stigmatized cope with episodes of stigmatization similar to the way individuals who do not possess a stigmatizing trait experience any other psychological threat (Crocker, Major, & Steele, 1998; Miller & Major, 2000). Based on this new information, the primary aims of this dissertation are to present a contemporary perspective of the stigma process, and to examine the appropriateness of this model when it is applied to the case of help-seeking for hearing difficulties, and to the case of disclosing hearing loss in the workplace.

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[1] It is important to note the differences between: individuals who acquire a hearing loss in adulthood; and those individuals who are born deaf, who have a profound hearing loss, who may use sign language (i.e., the culturally Deaf).

# Literature review

# Literature review

The objectives of this chapter are to familiarize readers with the basic concepts of stigma, and its manifestations in people who have hearing loss. First, several of the most influential definitions of stigma are presented, and key dimensions of stigma are outlined. Next, is a description of some of the historical stereotypes assigned to people who are deaf and speculate on how these may influence the experiences of people who have hearing loss. That is followed by the presentation of two identity integration models (one for adaptations following onset of disability, and one specific to changes that come with age) that help us understand how self-concept contributes to the experience of stigma. And finally, two models of stigmatization are outlined: one model that originated with social psychologists who asserted that coping with stigma is very similar to coping with stress; and one model that emphasizes sociological influences on the stigmatization process.

## Definitions of stigma

Individuals are stigmatized when they possess, or are thought to possess, an attribute or characteristic that conveys a social identity that is devalued in a particular social context (Crocker, et al., 1998). Stigmas are a complex and multifaceted phenomenon. In Erving Goffman's essay *Notes on the management of a spoiled identity*, the author defined stigma as "an attribute that is deeply discrediting" that reduces the individual "from a whole and usual person to a tainted, discounted one" (p.3: Goffman, 1963). It is generally agreed that stigmatization may occur when two groups of people exist: *insiders* (people who have a stigmatizing trait); and *outsiders* (people who do not have this trait). When the outsiders (i.e., the governing group) perceive a trait to be stigmatizing, they might devalue, prejudice and discriminate against the insiders (Dovidio, et al., 2000; Heatherton, Kleck, Hebl, & Hull, 2000). Stigmatization can affect the cognition and behaviours of the insiders, and can figure into the evolution of the self-identity of people who possess stigmatizing traits (Dovidio, et al., 2000; Miller & Major, 2000).

Among stigma theorists, there is a general consensus that stigma is a social construction (Crocker, et al., 1998; Dovidio, et al., 2000; Goffman, 1963). The social and physical environments, as well as macro-level socio-political factors determine which traits are perceived to be stigmatizing (Link & Phelan, 1999, 2001). According to Goffman (1963), the relationship between a trait and a stereotype is at the root of stigmatization. It is in social settings that the requisite “relationship between an attribute and a stereotype” is established. Goffman spoke of a discrepancy between one’s “virtual social identity” (how a person is viewed by society) and their “actual social identity” (how a person views himself or herself) (p.2: Goffman, 1963). Social stigma (sometimes referred to as *public stigma*) occurs when the general public reacts to a group of people based on stigmatizing attributes about that group (Watson, Corrigan, Larson, & Sells, 2007). Jones, Farina, Hastorf, Miller, and Scott (1984) generally supported Goffman’s assertion that social environments define what is stigmatizing, and the circumstantial and situational factors inherent to social settings impact upon stigma. Notably however, Jones et al. expanded upon Goffman, by suggesting that stigma sometimes results in an individual who possesses stigmatizing traits devaluing himself or herself, something that is now referred to as *self-stigma* (Major & O'Brien, 2005). Self-stigma occurs when individuals who are members of a stigmatized group turn against themselves by directing prejudicial attitudes inward (Watson, et al., 2007).

## Dimensions of stigmas

Goffman (1963) proposed a taxonomy of stigmas: “abominations of the body” (e.g., amputated limbs), “blemishes of individual character” (e.g., ex-convicts), and “tribal identities” (e.g., some religious belief systems). Stigmatizing marks or attributes of this kind brought discredit to individuals who possess them (Goffman, 1963). Jones et al (1984) identified six key dimensions of stigmas. Several of the dimensions identified by Jones et al. are particularly relevant to the stigma associated with hearing loss. *Concealability* refers to the extent to which a stigmatizing trait is apparent to others. As many authors have reported, the presence of hearing loss is often c*oncealable* to others (Gagné, Southall, & Jennings, 2009; Hétu, 1996). The *course of the mark* refers to the possibility that the attribute may become more prominent over time. Hearing loss acquired in adulthood most often starts out concealable, and becomes more prominent (depending on the extent to which the individual is successful at incorporating rehabilitative strategies into daily routine). *Disruptiveness* is in reference to how the stigmatizing trait interferes with social interactions. This dimension of stigmas has obvious ramifications for people with hearing loss. *Aesthetics* relates to the level of unattractiveness of the stigma as perceived by others. On more than one occasion, Kochkin has reported that cosmetics detract some people from using hearing aids (Kochkin, 1993, 1994, 2000, 2007). *Origin* refers to the perceived responsibility of the individual in acquiring or creating the trait. Although there is an absence of empirical evidence on this subject, it is reasonable to assume that the intensity of stigmatization varies based on type of hearing loss (e.g., presbycusic hearing loss, and its association with ageing may be more stigmatizing than a hearing loss that was caused by an accident). Finally, *peril* relates to the perceived danger of the stigma to others in the social setting. Of these dimensions of stigma, Crocker and colleagues (1998) proposed that concealability and origin (i.e., controllability) are the most influential in terms of giving rise to stigmatization.

## The nature of hearing loss stigma

Stigma is a social phenomenon that is greatly influenced by both historical and cultural forces (Dovidio, et al., 2000). Although it is difficult to pinpoint the exact origins of a stereotype, many of the present day stereotypes attributed to people with hearing loss date back to prejudicial attitudes held against people who were deaf in Ancient Greek societies (Higgins, 1980). Aristotle, for example wrote that people who could not hear were speechless, and most likely senseless. At this time, the word used to express that someone is speechless, was identical to the word used to express that someone is senseless. This is a good example of how language used in social settings can influence social and self-stigma, an observation made by Goffman (1963). In the present day, we live in a society that relies upon “traditional communication” (i.e., vocalized speech). Should one encounter a person who is unable to communicate in a “normal” manner, one might revert to (rely upon) historically and culturally constructed stereotypes in order to understand what is perceived to be “deviant” behaviours. Like other cultural beliefs, prejudicial beliefs are transmitted from one generation to the next. In his examination of the experiences of people who are Deaf, Higgins (1980) provided compelling evidence that derivations of ancient prejudices toward people who are deaf continue to impact upon the present day community of people who have hearing loss. In many ways, the stereotypes about people who are deaf have impacted upon the rights of people who have hearing loss. In North America for example, people who are Deaf have endured a range of prejudicial and discriminatory policies and practices, related to land ownership, the right to marry and right to vote, just to name a few. As with some other chronic impairments (most notably vision), the general public does not easily make the distinction between absolute and partial loss of function (Bunting, 1981). Thus, the general public may stigmatize people with hearing loss in the same manner that they would stigmatize people who are Deaf. For example, the general public associates hearing loss with reduced intellectual capacity and mental health problems, two stereotypes commonly associated with people who are deaf (Waridel, 1993).

## Individuals with hearing loss

Hearing loss is one of the most commonly occurring impairments in Canada. According to the National Advisory Council on Aging (1997) hearing loss affects approximately 4 of every 100 Canadians. The prevalence of hearing loss gradually increases with age (Erber, 2002; Heine & Browning, 2002). While less than 1% of persons under the age of 25 years of age report hearing impairment, that percentage increases to 47.5% of persons over the age of 85 (Statistics Canada, 1992), making hearing loss one of the most commonly reported chronic disabilities for older adults (National Council on the Aging, 1999; Statistics Canada, 1992; Weinstein, 2000).

Like many other chronic health conditions, there is a stigma associated with acquired hearing loss. In part due to association with deafness and ageing processes, there exist several stereotypes about people who have hearing difficulties. In industrialized countries, people with hearing loss are perceived to be old (Oyer & Oyer, 1985), less interesting than people with normal hearing (Hétu, 1996; Jones, et al., 1984), and less intelligent than those with normal hearing (Heine & Browning, 2002). Stigma theorists assume that stereotypes are known to individuals who possess stigmatizing attributes (Goffman, 1963). It is generally accepted that stigma has an impact on how individuals manage all social situations, including workplace interactions, leisure pursuits, family life and intimate relations (Crocker, et al., 1998; Gagné, et al., 2009; Jones, et al., 1984). To avoid potentially stigmatizing situations, many people employ (mal)adaptive coping strategies such as concealment, denial, avoidance, and social isolation (Hallberg & Carlsson, 1993; Hallberg & Barrenas, 1995; Hétu, Getty, & Waridel, 1994; Major & Schmader, 1998; Steele, 1997).

## Identification with disability and age

There is a general consensus that identity is central to the perception of stigma and subsequent responses to being stigmatized. Individuals possess a self-identity and (more than one) social identities (Tajfel, 1981). At its core, stigma is the devaluation of one's identity (Crocker, et al., 1998; Goffman, 1963; Jones, et al., 1984). Modern conceptions of identity typically describe the self as a reflexive entity (for which the individual is responsible), this reflexivity is continuous, and the self formulates a trajectory of development, from past to anticipated future (Giddens, 1991). Stigma can distort self-reflections and impact upon an individual's trajectory. Stigma involves the identities of people who possess stigmatizing traits being devalued by others, and the people who possess stigmatizing traits devaluing themselves. Although it is not always the case, being the object of stigmatization can lead to losses in self-worth and self-esteem, isolation and depression (Hétu, 1996).

The discussion of how possessing a stigmatizing trait impacts upon identity is closely tied with symbolic interactionism (Blumer, 1969; Mead, 1934). According to symbolic interactionism, people and actions are considered to be "social objects" that become meaningful through social interactions. Humans are continuously (consciously and not) interpreting how others in social settings view and respond to one's social identity. This practice influences self-concept (Markowitz, 2005). Mead (1934) conceived the "looking glass self ", a metaphor that suggested that *we often see ourselves as others see us*. Over the years this metaphor as been modified slightly to be, *we see ourselves as we believe others see us* (Cioffi, 2000). Based on symbolic interactionism, social deviance is interpreted through spoken language and symbols present in social settings (Becker, 1963). The application of deviant labels to an individual (or even the knowledge that other people in one’s immediate surroundings *may* attribute a trait to a stereotype) changes self-perceptions and modifies inner dialogue, thus altering interpretations of social experiences. According to this conceptualization, the meanings assigned to social interactions determine responses to stigmatizing situations (Mead, 1934).

In the United States of America, Kathy Charmaz reported that older adults with chronic illness avoid disclosure as a way of preserving “control of identity, control over information, control over emotional response, and control over one’s life” (p. 110: Charmaz, 1991). Charmaz also wrote that “The ill individual draws upon past social experiences, cultural meanings and knowledge to engage in a mental dialogue about the meanings of present physical and social existence, specifically, the emergent indications of identity elicited by illness." (p. 170: 1983)

According to a symbolic interactionist approach, the onset of illness can initiate the formation of new, modified or alternative identities, and subsequent forms of social interaction. It is now widely accepted that humans have several social identities, each of which becomes more or less dominant depending on the social situation (Ashmore, Deaux, & McLaughlin-Volpe, 2004; Deaux, 1996; Hewstone, Hassebrauck, Wirth, & Waenke, 2000; Schmid, Hewstone, Tausch, Cairns, & Hughes, 2009). Various social scientists have conceived theories and conceptual models that outline how stigma and identities may interact. Two of these will be described below.

One model by Cass (1979) has received a certain degree of acceptance within the gay-lesbian-transgender literature (Corrigan, 2005). Cass proposed a series of landmarks inherent to integrating a gay-lesbian-transgender identity into the self-concept. Many of the identity transformation processes described by Cass are relevant to the discussion of people with acquired hearing loss. According to Cass (1979), there are six landmarks of integrating a stigmatizing trait into one's self-concept: *identity confusion, identity comparison, identity tolerance, identity acceptance, identity pride and identity synthesis.* In the first two stages, the person with the stigmatizing trait begins to question their identity. The person is aware that manifestations of their stigmatizing trait distinguishes or sets them apart from "outsiders", and they begin to feel isolated or set apart from other people in their daily activities who do not seem to have the same problems. Over time, the person with the stigmatizing trait begins to tolerate this new identity, and searches out opportunities to associate with other people who also have this stigmatizing trait in order to learn how to adapt to these new challenges. Identity tolerance is followed by identity acceptance, when the person selects certain people in their environment to whom they will disclose their stigmatizing trait. This decision is influenced by a judgment regarding how another person is likely to respond to this disclosure. Some people proceed to identity pride, when they immerse themselves in activities for people who possess this stigmatizing trait. Through identity pride, one reaches identity synthesis, whereby the identity associated with the stigmatizing trait makes up one piece of the total self. In many ways, Cass' model is similar to the normalization model proposed by Hétu (1996), described in Chapter One.

An alternative to Cass' perspective on identity integration comes from the ageing literature. Within industrialized societies, the general public hold negative perceptions towards older adults and ageing (Palmore, 1982). In popular media, the process of ageing is often portrayed as a process that should be stopped or controlled. Meta-analyses reveal that older adults are perceived as frail, unattractive, ill (Barrett & Cantwell, 2007), worthless, perplexed, senile, ineffective, isolated and depressed (Palmore, 1999); self-centered, demanding (Hummert, Garstka, Shaner, & Strahm, 1994) and asexual (Kane, 2006). These stereotypes often result in older adults being marginalized and socially excluded.

Individual responses to the onset of any physical or social age-acquired change are closely tied with self-identity and self-concept. Whitbourne and Collins (1998) proposed the Identity Processing Model as an explanatory framework for adult development and ageing in relation to self concept over time. The Identity Processing Model has two fundamental processes: *identity assimilation* and *identity accommodation*. Identity assimilation is characterized by attributing age-related changes in a manner consistent with current conceptualization of the self, in terms of appearance, competence and health. Based on identity assimilation a middle-aged man who perceives himself to be young and vital, but has difficulty hearing his spouse in the next room, would attribute this difficulty to something other than potential hearing loss. In doing so, the man preserves current self-concept. Identity accommodation is characterized by incorporating age-related changes into the self-concept. Both processes are described as adaptive in some circumstances, while maladaptive in others. For example, a woman who has a profound hearing loss puts herself in harm's way if she always assimilates changes in hearing, and does not attempt to seek help. It would be equally unhealthy to accommodate situational or transient functional difficulties, as if they were related to ageing.

## Conceptualizations of the stigmatization process

According to Crocker and Garcia (2006), Goffman's treatise *Notes on the management of a spoiled identity* was published at an interesting point in the history of social psychology, because it coincided with the cognitive revolution of psychology. Goffman's work inspired many stigma researchers, however, because of the overlap with the cognitive revolution, the preponderance of subsequent research focussed on outsiders (i.e., stigmatizers). From the 1960s to the 1990s, stigma research was dominated by social psychologists who approached inter-group relations with a cognitive perspective. "*Categorization"* was the foundation of the cognitive approach to understanding stereotypes (Allport, 1954). All groups of people categorize, based on gender, age, vocation, appearance, etc., because by grouping items found in the environment into self-defined categories, it is easier to generate reasonable expectations of future events (Ottati, Bodenhausen, & Newman, 2005). Categorization also simplifies the generation of appropriate reactions to changes that occur in social environments. During this period of time, there were numerous important contributions to understanding how cognitive processes such as categorization can aggravate and intensify inter-group strain. However, research that attempted to characterize the experiences of people who possess stigmatizing attributes was rare. The direction of stigma research took a dramatic change when it was reported that African Americans did not always demonstrate lower self-esteem in response to stigmatization (Porter & Washington, 1979). This finding inspired a small group of researchers to investigate the experiences of people who are stigmatized by others, and likely served as an important antecedent to the conception of the stigma-induced identity threat model presented below. The second conceptual model described below illustrates an alternative viewpoint that originates in sociological literature.

## Stigma from a socio-cognitive perspective

Within the social sciences, there are several conceptualizations of stigma. Some authors have proposed that the experience of stigmatization is similar to the experience of stress (Crocker, Major, & Steele, 1998; Major & O'Brien, 2005; Steele, Spencer, & Aronson, 2002). For example, Major and O’Brien (2005) have described a stigma-induced identity threat model that is based on the transactional models of stress and coping (Lazarus & Folkman, 1984). The stigma-induced identity threat model is based on two premises. The first premise is that experiencing stigma is, in many respects similar to the way that we experience stress. The second premise is that stigma threatens one’s identity. Individuals are thought to approach situations that are potentially stigmatizing by appraising collective representations, situational cues and relevant personal characteristics. This model is described in much more detail in Chapter One.

## Stigma from a sociological perspective

*Sociologists* have examined deviance and stigmatizing traits by means of labelling theory (Becker, 1963). Based on symbolic interactionism (Blumer, 1969; Mead, 1934), labelling theory is an explanatory framework that accounts for the stigmatization of marginalized groups (Markowitz, 2005). As described earlier, symbolic interactionism proposes that there does not exist inherent meanings to social behaviours, but instead, the meanings of people and their actions are interpreted through language and symbols. An important presumption of labelling theory is that there are social groups in society that have power (i.e., a governing status) to dictate what does and what does not represent deviant behaviour. This governing group: a) has the resources to repel suggestion of deviant status, and b) acts in such a way to maintain their position of power. Conversely, it is assumed that the devalued groups are less able to repel accusations of deviance. Although early conceptualizations of labelling theory were criticized for overstating the importance of labelling and societal factors in the stigma process (Gove, 1970, 1975), Link and colleagues proposed a modified labelling theory (Link, Cullen, Struening, Shrout, & et al., 1989) that has received general support among mental health theorists. According to the modified labelling theory, learning stereotypes about behaviours, objects and attributes is an integral part of socialization. Familiarization with these views is strengthened through daily social interactions (Link, et al., 1989; Scheff, 1966). The general public comes to understand that people who possess certain attributes are devalued in society (e.g., through reporting in the media), and the general public discriminates against them (e.g., distances themselves from the individuals who have the stigmatizing trait). Certain stereotypes become personally relevant following confirmation that one possesses a stigmatizing attribute (e.g., diagnosis or entrance into treatment). Some of the stereotypes learned earlier in life suddenly becomes applicable to oneself, and results in reduced self-esteem. Labelled individuals expect to be devalued and discriminated against, and anticipate these outcomes when they enter into social settings. To avoid negative outcomes, individuals use a variety of strategies, such as withdrawing from certain social events, secrecy-disclosure or educating others about the nature of the stigmatizing attribute. The Labelling theory predicts that beliefs about societal attitudes *and* the coping strategies employed enhance anticipation of stigma, lead to negative outcomes (such as a restricted social network, and negative impacts on work opportunities). Thus, for people who possess a stigmatizing attribute, the stigma process becomes a self-fulfilling prophecy.

It is important to note that social-cognitive and sociological conceptualizations of stigma do not exist in isolation of one another. That is to say, the tenets and underlying assumptions of labelling theory and the stigma-induced identity threat model (and other stress process models) may be combined in some ways. For example, one could reasonably assume that the reduced self-esteem and negative outcomes predicted by labelling theory would result in elevated levels of stress experienced by the individual who possesses the stigmatizing attribute. Similarly, one could integrate a greater contribution of macro-level factors into several levels of the stigma-induced identity threat model (construals, coping responses and outcomes) without negatively impacting upon its predictatory properties. Further, the intent of introducing these two conceptualizations of stigma is not to enter into a discourse to determine which conceptualization is most right or most wrong. Rather, it was anticipated that acknowledging that there is more than one perspective on stigma, would allow for a more in-depth analysis of the findings from the studies presented herein. The overall purpose of this thesis is to examine how adults manage stigma following the onset of an acquired hearing loss.

## Overview of dissertation organization

The remainder of this dissertation is divided into five chapters. Chapter One is an article entitled "The application of stigma-induced identity threat to individuals with hearing loss". The purpose of this article was to apply a contemporary model of the stigmatization process to the case of individuals who have an acquired hearing loss, and to speculate on the implications for intervention services and service providers. This article has been published in the Journal of the Academy of Rehabilitative Audiology.

Chapter Two is an overview of the methodological protocols employed for the studies presented in Chapters Three and Four. Specifically, a rationale is provided for the research designs, sampling strategies, and data collection and analysis techniques employed in these studies. Finally, efforts employed to maximize the rigor of these two studies are described.

Chapter Three is an article entitled "Stigma: A negative and a positive influence on help-seeking for adults with acquired hearing loss". The purpose of the study was to better understand how stigma impacted upon the help-seeking activities of adults with an acquired hearing loss. This article has been published in the International Journal of Audiology.

Chapter Four is a manuscript entitled "Factors that influence disclosure of hearing loss in the workplace". The purpose of the study was to identify the factors that lead individuals to conceal or disclose their hearing loss in the workplace. This manuscript has been submitted to the International Journal of Audiology.

In Chapter Five, the Discussion, the findings from the three papers are summarized, the appropriateness of the stigma-induced identity threat model for the case of the stigma associated with hearing loss is explored, the implications of this research for health care practitioners is outlined, methodological choices are reflected upon, and avenues for developing and expanding this program of research are proposed.

Finally, concerning the organization of the thesis itself, the citations included within the body of the articles are referenced in (both) the article bibliography as well as in the dissertation bibliography. Also, the appendices cited within the articles as well as body of the thesis appear at the end of the thesis.

# Chapter One: Article 1 - The application of stigma-induced identity threat to individuals with hearing loss

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**Title:** The application of stigma-induced identity threat to individuals with hearing loss

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**Title:** The application of stigma-induced identity threat to individuals with hearing loss

## Abstract

Conventional wisdom within audiologic rehabilitation suggests that hearing loss stigma and the stigma associated with hearing aids act as a barrier to persons with hearing loss entering rehabilitative services. Regrettably, this knowledge has led to few investigations attempting to better understand this phenomenon. In recent years, researchers in the social sciences have made great strides to conceptualize “stigma” from the perspective of people who are the target of prejudicial attitudes. Most of these concepts proposed are applicable to the social stigma associated with hearing loss. In the present article we attempt to position hearing loss stigma within a model of stigma-induced identity threat. Based on this new information, we explore how intervention services could be modified to better serve individuals who show signs that their personal identity is diminished due to the fact that they have a hearing loss.

## Background

In North America, hearing loss stigma is a powerful social and psychological force. Stigma acts to delay the help-seeking behaviours of adults who develop hearing loss in a variety of ways. Hearing loss stigma has been associated with reduced self-esteem (Hétu, 1996); decreased levels of confidence, friendliness and intelligence (Doggett, Stein, & Gans, 1998; Hétu, 1996); constraints on social participation (Hétu, Riverin, Lalande, Getty, & St-Cyr, 1988); denial and/or minimization of the hearing problem (Hétu, Riverin, Getty, Lalande, & St-Cyr, 1990); concealment of hearing-related problems (Hallberg & Barrenas, 1995; Hallberg & Jansson, 1996; Hétu, Getty, & Waridel, 1994) and a reluctance to use hearing aids due to unfavourable cosmetics (Blood, 1997). The origins of contemporary perspectives on hearing loss stigma date back to Raymond Hétu's ground-breaking article *The stigma attached to hearing impairment* (Hétu, 1996). In this article, Hétu described how hearing loss stigma acts as a threat to one's social identity, and that reactions to stigma might be explained using *shame* as a foundational base. Hétu's (1996) treatise on the stigma associated with hearing loss has become one of the most influential documents on this topic in the domain of audiologic rehabilitation.

Evidence suggests that *The stigma attached to hearing impairment* (Hétu, 1996) was published during a time of strong growth in the quantity of stigma focused research. A keyword search for "stigma" in the database PsycInfo for the period 1860-1986 reveals just 585 articles. However, in the ten years prior to the Hétu article (1986-1996) 1133 articles are uncovered. While for the ten years following Hétu's article (1996-2006) the number of hits increases to 3716. An additional 1673 articles are flagged by adding the years 2006-2009. As a research topic, stigma is booming.

In the Social Sciences it is generally accepted that stigmatization occurs in social settings in which two groups exist: the outsiders and the insiders (Link & Phelan, 2001; Link & Phelan, 2006; Oyserman & Swim, 2001). The outsiders are a dominant group that possess and exercise power over the insiders. The insiders are subordinate to the outsiders because they possess an attribute that is distinct from the outsiders. Stigma research might take a number of different perspectives; however, the literature has two main trends. There is research that examines the *insiders* (i.e., the person being stigmatized). Research of this kind typically focuses on the psychological traits of insiders as opposed to aspects of the sociological scene. Conversely, there is research that investigates the outsiders and the macro-social level contributors to stigmatization. This research tends to focus on the impact of social inequities linked to behaviours of the stigmatizers. Discussion will be limited to the individual, and more specifically to the person being stigmatized.

In the past two decades, theories and models have been proposed that explain individual attempts to preserve self-integrity in response to identity threats (Crocker, Major, & Steele, 1998; Major & O'Brien, 2005; Steele, Spencer, & Aronson, 2002). For example, Steele, Spencer and Aronson (2002) described “stereotype threats”, the basic premise of which is that confirmation of cultural stereotypes leads to predictable negative consequences (e.g., anxiety, stress and under-performance on tasks) for individuals under observation. Crocker and her colleagues (1998) proposed the theory of “attributional ambiguity”. Here, the idea is that individuals with stigmatizing traits may attribute feedback (both positive and negative) from an ambiguously prejudicial source to be the result of stigmatizing trait, as opposed to alternative explanations. Simply stated, individuals who have stigmatizing attributes misinterpret events that occur in social settings. Finally Major and O’Brien (2005) proposed the “stigma-induced identity threat model”. According to this conceptualization, the intensity of perceived stigmatization is determined by the relevant stereotype, characteristics of the individual and of situational cues. According to Major and

O'Brien (2005) identity threat models "dominate" the current stigma research landscape. A more detailed description of the Major and O'Brien model will be provided in Chapter Two.

The stigma-induced identity threat model is founded on the assumption that the impact of stigmatization is determined by the motives of the person who possesses the stigmatized attribute, by their understanding of the particular social scene, and by their understanding of what other people think of them (Major & O'Brien, 2005). Although not explicitly incorporated into his model of stigma, to his credit Hétu (1996) addressed the issue of social identity and (albeit briefly) described how elements inherent to the situation influence one's perception of stigmatization. Although an introduction to this model will likely lead to insights into how to optimally address stigma within the realm of audiologic rehabilitation, the primary intent of this article is to extend understanding of hearing loss stigma by way of introducing a contemporary stigma identity threat model. Discussion will be limited to the perspective of people who acquire a permanent hearing loss in adulthood. Overall, the goals of this paper are to a) offer a brief summary of hearing loss stigma; b) present the stigma-induced identity threat model and incorporate ideas about hearing loss stigma into this general conceptualization of stigma; and c) reflect on the appropriateness of this model for the domain of rehabilitative audiology.

## Hearing loss stigma

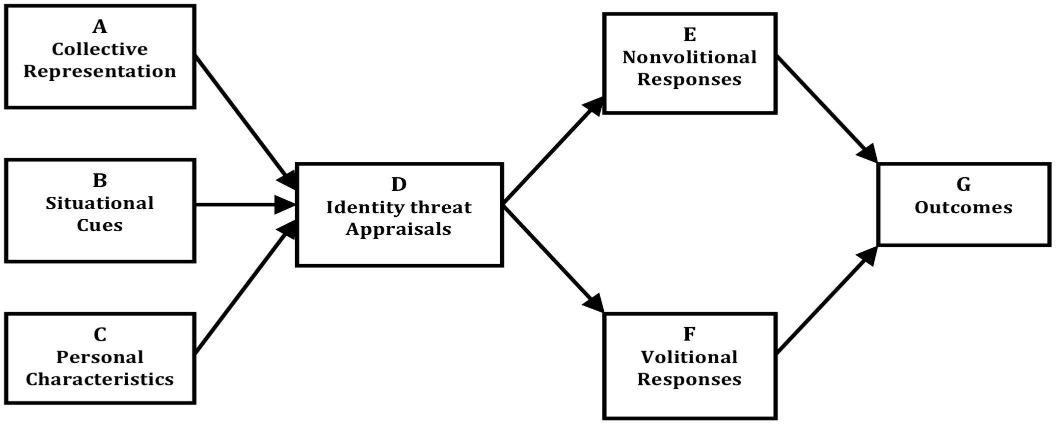
In ancient Greece, the word *stigma* represented the cuts and burns inflicted on people thought to be traitors, criminals or slaves (Goffman, 1963). Over time, the definition of stigma evolved to focus on how these marks or attributes designate the bearer of a spoiled identity, or someone who is valued less in society (Goffman, 1963). In *Stigma: Notes on the management of a spoiled identity,* Goffman (1963) proposed that stigmatization takes place when a person possesses an attribute (e.g., abominations of the body, of the character or of race / religion) that is other than what is anticipated, and therefore undesirable, leading this person to be devalued as a human being. For the purpose of this paper, stigma refers to the possession of, or belief that one possesses an attribute or characteristic that conveys a social identity that is devalued in a particular social context (Crocker, et al., 1998).

Goffman (1963) reported that people with hearing loss often experience archetypal elements of stigmatization. Hearing difficulties (the devalued attribute) is often generalized to other aspects of a person's social identity. Specifically, the reduced capacity to hear is often misunderstood as an intellectual challenge or deficiency in personality ⁄ character (Goffman, 1963). One key dimension of stigma that is particularly relevant to the discussion of stigma associated with hearing loss is the capacity for the stigmatized person to conceal the stigmatizing trait from others (Jones, Farina, Hastorf, Miller, & Scott, 1984). Many individuals who have a concealable stigma attempt to "pass as normal", in effect keeping the devalued attribute a secret (Goffman, 1963). In the case of a progressive hearing loss however, over time the stigmatized attribute becomes more apparent to communication partners. Therefore, the inherent risks associated with concealing hearing loss gradually become greater, as do the penalties of being caught in this deception.

A second key dimension of stigma that is particularly relevant to the discussion of hearing loss is the extent to which a person's hearing difficulties become disruptive in social settings. Disruptiveness is a subjective measure of the extent to which a stigmatizing condition interferes with the normal course of a social interaction. Dovidio, Major and Crocker (2000) reported that people who have stigmatizing conditions make poor partners for social interactions. One particularly distressing aspect of stigmas is that the individual is aware that the quality of his or her social identity is being devalued, yet the person is uncertain as to whether this evaluation is based on their stigmatizing attribute (Goffman, 1963). This uncertainty surrounding the reasoning for mistreatment imparts a constant stress on the individual (Miller & Major, 2000). Goffman (1963) also proposed that it is particularly psychologically difficult for people who “bought into“ prejudicial attitudes about a stigmatized group early in life to subsequently become a member of that stigmatized group later in life. Individuals who acquire hearing loss in adulthood might experience difficulties of this kind.

## Model of stigma-induced identity threat

According to the model of stigma-induced identity threat proposed by Major and O'Brien (2005), stigmatization can threaten one’s social identity. These authors suggested that experiencing a potentially stigmatizing event (and the coping responses that follow) is fundamentally similar to experiencing a stressful situation. A block diagram depicting the conceptualization of stigma as proposed by Major and O’Brien (2005) is shown in Figure 1. The core element of this model is box D, appraisals of identity threat. When confronted with a potentially stigmatizing situation, the person who possesses the stigmatized attribute appraises (consciously or at a pre-conscious level) the threat to his or her social identity. This is an “on the spot” assessment of the meaning and significance of this mistreatment (i.e., stigma). If the demands of the situation tax or exceed available personal resources, the event is deemed threatening, thereby creating need for a response. The appraised identity threat is based on three construals: the collective representation present (box A), situational cues inherent to this event (box B), and personal characteristics of the person who possesses the stigmatizing attribute (box C). The person responds to a threatening event with nonvolitional responses (box E), and with volitional responses (box F). The outcomes



Stigma-induced identity threat model (Major and O’Brien, 2005) (box G) of coping responses likely feed back to the construals level of the model (i.e., to the collective representations, situational cues and personal characteristics) and the appraised identity threat levels (note: although these feedback loops exist, they are not displayed in the visual representation of Figure 1).

Note that the design of this specific stigma-induced identity threat model is general enough to consider a wide range of stigmatizing traits and individual characteristics. We consider this to be a strength of the model. For example, concerning hearing loss, it is likely that characteristics such as the age of onset of hearing loss, the degree and type of hearing loss, and the mode of communication used will have an influence on the magnitude and the type of identify threat a person with hearing loss will experience (these factors are grouped under the personal characteristics component of the stigma model proposed by Major and O'Brien, 2005).

## Collective representations

Collective representations are the shared (societal) understandings and beliefs about stigmatizing conditions (Crocker, 1999). As a first approximation, this term can be thought of as being synonymous with the term stereotype. Evidence suggests that currently, in Western societies, to have a hearing loss is to be perceived by others as unacceptably different (Erler & Garstecki, 2002). Although most collective representations about hearing loss in North America are negative, in some communities such as the Deaf community hearing loss is not devalued.

From a general perspective, even toward the end of the twentieth century, there remained a lack of understanding of the manifestations of hearing difficulties (Garstecki, 1990). Hearing loss is often being mistaken for senility (Oyer & Oyer, 1985). Communication partners often perceive hearing loss to be annoying because of the disruptive influence that it has on the natural flow of social interactions (Jones, et al., 1984). To make matters worse, commonly employed approaches to rehabilitation (i.e., hearing aids and hearing assistance technologies) act as symbols of stigma that perpetuate stereotypes (Goffman, 1963). The "hearing aid effect" (i.e., negative perceptions of hearing aid users) has been described by numerous authors (Blood, Blood, & Danhauer, 1977; Doggett, et al., 1998; Kochkin, 2007). Low hearing aid utilization rates by people with an acquired hearing loss suggest that many adults "buy into" prevalent collective representations and choose to attempt to conceal their hearing difficulties rather than risk being perceived as old, weak or disruptive (Kochkin, 2007).

Recent evidence suggests that some people might be more resilient to the negative effects of stereotyping than others. Link and Phelan (2001) suggested that the extent that one "buys into" a collective representation (in part) determines resilience to threatening situations. For example, based on the stigma-induced identity threat models, a person with an acquired hearing loss who buys into the belief that people with hearing loss have intellectual deficiencies, would likely experience elevated levels of stress during occasions when he or she is stigmatized based on intellect. Elevated levels of stress would in turn prompt expenditures of cognitive, psychological and emotional resources to cope with this threat, perhaps making the person more vulnerable to subsequent stigma threats. By contrast, it is also reasonable to suggest that a person who does not buy into the link between hearing difficulties and intelligence will maintain proportionately lower levels of stress during the same event, would preserve cognitive, psychological and emotional resources, and may build up resilience to stigmatization. Identity threat appraisals have obvious implications for audiologic rehabilitation. This will be described in more detail in the clinical implications section.

## Situational cues

Situational cues are matters related to the physical and social environment inherent in a potentially stigmatizing event. Situational cues are influenced by the meanings assigned to situations or events by the key players (Crocker & Quinn, 2000). Related to audiologic rehabilitation, the relevance of *physical* situational cues is found in Hallberg and colleague's examination of coping with situations of handicap (Hallberg & Carlsson, 1993; Hallberg & Barrenas, 1995). In these studies, background noise (i.e., a physical cue) was appraised in some instances to be problematic (and stigma inducing), while relatively manageable in other instances. In one study, Hallberg and Barrenas (1995) reported that the background noise found on the shop floor to be a manageable situational cue, because co-workers were in the habit of speaking loudly to one another. This situational cue resulted in few communication breakdowns, presumably little stress and little risk of stigmatization. By contrast, in a second study, (Hallberg & Carlsson, 1993) participants expressed that the noise typically found in meetings (e.g., shuffling papers) caused elevated levels of stress. This background noise caused communication breakdowns, fear of the need to disclose hearing loss, and potentially an increased risk of stigmatization. These two examples demonstrate how one *physical situational cue* (i.e., background noise) can result in two distinctly different levels of stress.

An example of the impact of *social situational cues* is found in Hétu's (1996) examination of adult male workers with hearing loss. While workers often concealed or denied hearing loss at work, the same men admitted (albeit reluctantly) difficulty hearing at home. Disclosure of hearing loss varied across different scenarios. This finding was corroborated in a study that examined disclosure / nondisclosure of epilepsy. Troster (1997) reported that willingness to disclose epilepsy was dependent upon a subjective evaluation of 1) the perceived risk of unwittingly being detected or identified as a person who has epilepsy; and 2) the anticipated consequences of disclosure. Again, willingness to disclose this stigmatized attribute varied across different scenarios.

The salient point is that the level of stress induced by situations of stigma is determined in part by aspects of the physical and social environment, and by meanings assigned to interactions by communication partners. Cues inherent to the situation play a key role in identity threat appraisals. For example, a person without paid employment may experience an elevated level of stress due to stigmatization during a job interview, compared to the stress induced by stigmatization while purchasing a carton of milk at their local corner store.

## Personal characteristics

Within the context of the model, personal characteristics are attributes or aspects of a person that influence how one appraises a situation of stigma-induced identity threat. These might be any characteristic that distinguishes one person from another. Thus, this category is comprised of (but not limited to): age, gender, personality, ethnic and/or cultural identity, presence or absence of other stigmatizing traits, religious beliefs and practices, marital status, significant life events, etc.

A growing body of evidence in the social sciences suggests that personal differences impact how we appraise situations of stigma (Crocker, et al., 1998; Major & O'Brien, 2005; Steele, et al., 2002). Similar findings have been reported in rehabilitative audiology. For example, women with hearing loss are less likely than men to allow stigma to act as an obstacle to social involvement (Erdman & Demorest, 1998; Garstecki & Erler, 1999). Relative to men (and to younger women), the stigma associated with hearing aids tends to become less important to *women* as they age (Erler & Garstecki, 2002; Gilhome Herbst, Meredith, & Stephens, 1990). Younger adults are more likely than older adults to reject hearing aids because of stigma (Kochkin, 1993). Differences in help-seeking behaviours have been reported based also on personality type. In this case, Cox, Alexander and Gray (2005) found that compared to the typical adult, individuals who actively seek to purchase hearing aids tended to have a greater internal locus of control. It has also been suggested that a positive attitude is associated with greater hearing aid use (Goldstein & Stephens, 1981; Hickson, Hamilton, & Orange, 1986).

A complete analysis of the personal characteristics that influence behavioural responses to stigma is beyond the scope of the current discussion. Nonetheless, the examples of individual differences presented above suggest that personal characteristics may affect the appraisal of identity threat and the subsequent coping responses arising from a stigmatizing situation.

## Identity threat appraisals

According to the stigma-induced identity threat model proposed by Major and O'Brien (2005), identity threat appraisals are multi-factorial assessments made by a person when confronted with a stigmatizing event. The individual who possesses the stigmatized trait evaluates his or her motives in the particular social setting, their understanding of the particular social event, and their understanding of how they are perceived by the other people present to determine if he or she has the resources to cope with this threat (Lazarus

& Folkman, 1984). If the situation is appraised as “threatening” (as described earlier), the individual will formulate (a) coping response(s). As illustrated in Figure 1, responses to appraised identity threats are modulated by collective representations, personal characteristics and situational cues relevant to the specific social scene (Major & O'Brien, 2005).

## Coping responses

For the purposes of this article, coping responses can be thought of as efforts made by an individual to regulate emotion, thought, behaviour, physiology and the environment in response to a stigma-induced identity threat (Miller & Kaiser, 2001). The section that follows describes and provides examples of volitional and nonvolitional responses to appraised stigma threats (illustrated as boxes E and F respectively in Figure 1). Moreover, this section will describe how this conceptualization of coping is relevant to hearing loss stigmatization. It should be noted that some coping responses might be assigned to both volitional and nonvolitional categories. This apparent ambiguity is consistent with the contention that stigmatization and responses to stigmatization are highly individualized and situation specific.

### Volitional responses

Volitional responses are voluntary efforts to change or adapt to stressful situations. When confronted with an appraised identity threat an individual might attempt to change the course of a stressful event by problem-solving, or by regulating emotions (Miller & Kaiser, 2001). For example, one might attempt to *adapt* personal behaviours in social interactions as a means to manage a stressful event (Shih, 2004). Evidence suggests that being assertive or persistent is useful to make oneself less vulnerable to the stigmatizing behaviours of others (Hebl & Kleck, 2000; Shih, 2004). This strategy has also been reported in rehabilitative audiology. Hallberg and Barrenas (1995) reported that men with an acquired hearing loss often attempted to control their social interactions by making modifications to verbal and non-verbal communication, structuring difficult auditory situations (e.g., requesting help from their spouse) and maintaining social interactions (e.g., persistence). These volitional responses likely reduce the number of communication breakdowns, and disruptiveness of hearing loss, thereby deflating the stress of the situation.

Alternatively, if a person with hearing loss is repeatedly excluded from social interactions with a specific group of people, he or she might decide to search out new social opportunities. There is a tendency for some people who are stigmatized to be drawn into peer-group involvement (Goffman, 1963). This effect has been investigated for adults with acquired hearing loss (Gagné, Jennings, & Southall, 2009; Southall, Storck, & Hannan, 2008). In a recent study we interviewed hearing health advocates to explore their perspectives on the influence that stigma has on help-seeking behaviours. We found that adults with an acquired hearing loss may find a sense of community and social belonging in peer support groups (e.g., Hearing Loss Association of America or Canadian Hard of Hearing Association). Participants in this study also explained that involvement in these groups allowed for the development of healthy attitudes about hearing loss, and the social support received enabled many respondents to seek out audiological services without feeling stigmatized. Major and O'Brien (2005) reported that participation in peer-groups is often accompanied by benefits including educational and instrumental support, social validation and a sense of belonging. The activities and educational campaigns engaged in by peer-groups might also lower feelings of helplessness and stress (Baker, 2002; Morrell, 2002).

A more passive volitional response to a stigmatizing event is to deliberately remove oneself physically or psychologically from the stressful situation. Numerous authors have reported avoidance strategies by individuals who are placed in stigmatizing situations (Hallberg & Carlsson, 1993; Hallberg & Barrenas, 1995; Major & Schmader, 1998; Steele, 1997). Hallberg and Barrenas (1995) observed that men with noise induced hearing loss frequently “avoided” by withdrawing, pretending to understand during interactions or guessing during interactions. A different strategy involves individuals who are stigmatized dissociating their self-esteem from the domains in which they are being negatively stereotyped, thereby protecting their pride and self-esteem (Major & Schmader, 1998). For example, it has been found that some older adults who perceive ageist stereotypes consciously disregard their own chronological age and focus on perceived physical and psychological age (Montepare, 1996). Again, the same strategy is reported in rehabilitative audiology. People with hearing loss often deny hearing difficulties and claim that communication problems are due to the environment (i.e., noise) or an ineffective communication partner (Jones, Kyle, & Wood, 1987).

## Nonvolitional responses

Nonvolitional responses to stress are involuntary changes in physiological and emotional functioning made by an individual to cope with stressful situations. Appraised identity threats have been associated with numerous changes in physiological functioning, including anxiety (Spencer, Steele, & Quinn, 2002) elevated blood pressure (Blascovich & Mendes, 2000) and arousal (Ben-Zeev, Fein, & Inzlicht, 2005). These studies indicate that the stress associated with stigma can cause adaptive and maladaptive changes in bodily functions. Perhaps more relevant to the present article, an appraised stigma identity threat can prompt involuntary emotional responses. Two examples will be described below. First, Feldman and Swim (1998) reported that recurring situations of stigmatization can lead some people to respond with automatic vigilance. This involuntary response involves the individual who possesses the stigmatized trait to establish a heightened sensitivity to stigmatization. A second example of an involuntary response to an appraised identity threat is preconscious avoidance. Mogg, Bradley and Hallowell (1994) reported that some individuals are able to block out prejudicial attitudes at the preconscious level in order to cope with stigma related stress. These authors reported that avoidance of cancer-related words (i.e., a nonvolitional response to the stigma associated with cancer) was positively correlated with positive adjustment to the disease, while volitional avoidance was not. The clinical implications of volitional and nonvolitional responses to an appraised identity threat will be addressed later in this article.

## Outcomes

Within the context of the present discussion, outcomes can be thought of as the result of volitional and nonvolitional responses to an appraised identity threat. This section will address how appraised identity threats might influence people in their everyday life. To illustrate this point, two outcomes of hearing loss stigmatization have been selected, namely: self-esteem and communication satisfaction. These topics were selected because they are often associated with hearing loss stigma, and because they illustrate a range of outcomes that might result from stigmatization (Doggett, et al., 1998; Hétu, 1996).

### Self-esteem

One possible outcome of repeated identity threats is change to one's self-esteem. Self-esteem might be described as confidence in your own merit as an individual. There remains little doubt that many individuals who are stigmatized experience reduced self-esteem. Link and his colleagues (Link, 1987; Link & Phelan, 2001) have proposed a process to illustrate the connections between self-stigmatization and self-esteem. According to these authors, reductions in self-esteem begin when people who are stigmatized become aware that they possess a stigmatizing mark and might continue to decline if the individual agrees with or “buys into” these societal attitudes. Declines in self-esteem become harmful if the individual self-discriminates or acts on these beliefs. Traditionally, it was assumed that stigmatization invariably led to reduced self-esteem. However, as alluded to earlier, contemporary research indicates that the effects of stigmatization on self-esteem are not always negative (Corrigan & Watson, 2002). Positive outcomes resulting from stigmatization are being reported with more and more regularity (e.g. Lockey, Jennings, & Shaw, 2008; e.g.Shih, 2004; Southall, Gagné, & Jennings, 2010).

### Communication satisfaction

A second possible outcome of recurring identity threats are changes to communication satisfaction. Communication satisfaction is the fulfillment derived when the need for human social contact is met. Erber (1988) identified several aspects of verbal interactions that influence communication satisfaction. These include 1) the amount of new information exchanged; 2) the level of conversation fluency (turn taking; number of communication breakdowns; 3) the proportion of time spent on repairing breakdowns; and time spent for a meta-communication. The following brief discussion provides a range of possible communication satisfaction outcomes within the context of the stigma associated with hearing loss.

The extent to which an individual buys into a given collective representation will likely influence communication satisfaction outcomes. For example, an adult who buys into the collective representation that hearing loss is a sign of frailty might decide to conceal hearing difficulties in certain social settings. A commonly used strategy to conceal hearing difficulties is to dominate the conversation. This strategy limits the likelihood of misunderstandings, the need to reveal hearing loss and opportunities for stigmatization. Yet, this strategy might also limit turn-taking and the amount of new information being exchanged. Thus, according to the verbal interaction cues identified by Erber (1988), this strategy might result in lower communication satisfaction.

On the other hand, if a person does not buy into the above-mentioned collective representation, they might decide to disclose their hearing loss in certain social settings. Communication partners seem to respond favourably to disclosure of hearing loss. Blood (1997) reported that people who acknowledged their hearing loss were assessed favourably on personality, adjustment and employability. Disclosure of hearing loss however might result in a reduction of communication satisfaction if disclosure is accompanied by an escalation in the number of communication breakdowns (Gagné, Stelmacovich, & Yovetich, 1991). Therefore, we recommend that disclosure of hearing loss be accompanied by specific repairs strategies selected to reduce the number of communication breakdowns.

## Implications for practice

Stigma serves as a formidable obstacle to many adults with hearing loss who could benefit from hearing health care services. The primary goal of this article is to present a specific stigma identity threat model and reflect on the appropriateness of this model to the domain of rehabilitative audiology. The stigma-induced identity threat model (Major & O'Brien, 2005) helps us understand stigma and the effects of stigma from the perspective of the insiders. The implications for rehabilitative audiology are numerous and far-reaching.

The goal of this section is to briefly discuss potential applications of this conceptual model to the practice of clinical audiology. The intent is not to recommend specific intervention programs or assessments that address aspects of identity threat, but rather to discuss how existing services within rehabilitative audiology might be viewed from the perspective of the identity threat model. First, we describe how this model might be used to inform clinicians about hearing loss stigmatization so that they might better serve clients. Second, we describe how this conceptual model might provide clinicians with a fresh perspective on programs that they are currently offering.

Adopting the use of the stigma-induced identity threat model into clinical settings will likely provide clinicians with a better understanding of the stigmatization process, from the perspective of people who are stigmatized. We expect that this information would serve as a useful resource for clinicians. With this information clinicians might counsel clients on the situational nature of stigma threats, the role that they play in these situations, help-seeking and most effective coping responses. A better-informed client is (in itself) a useful rehabilitative strategy. Clinicians might also incorporate general information about the stigmatization process into the services presently offered to clients. For example, even a basic introduction to the concepts held in the stigma-induced identity threat model may help clients better understand the stigmatization process and its manifestations. This knowledge may enable clients to recognize "threatening" situation, and employ appropriate coping strategies. Clinicians might assist clients use the ideas proposed in the model to better analyze specific situations that are identified as difficult. For example, it may be helpful for a person with hearing loss to understand (become conscious) that the reason they exhibit non-volitional responses (e.g., swallow breathing or sweating) in certain settings (e.g., business meeting with their boss) may be attributable to the fact that they experience a high-level of identity threat in that situation (perhaps because the person with hearing loss has opted not to disclose the hearing loss to his or her superior).

We feel that the stigma-induced identity threat model provides clinicians with a useful framework to consider rehabilitation services presently being offered to people who exhibit some level of identity threat due to their hearing loss. One current area of investigation in rehabilitative audiology is the effect that personality has on hearing aid use (Kricos, Erdman, Bratt, & Williams, 2007). According to the stigma-induced identity threat model, personality (and other psychological characteristics) play a key role in the appraisal of identity threat. This is crucial information that clinical audiologists and their clients should consider when they are planning intervention programs. It may be useful for the clinician to assess (formally or informally) the client's propensity for identity threat in different activities of daily living. Candidates who do not experience identity threat in various social settings may be better candidates for hearing aid use. On the other hand, clients who are susceptible to experiencing identity threats may be candidates for intervention programs geared toward diminishing identity threats before they are encouraged to use amplification systems in their everyday activities. Similarly, it is important for clients to be aware of all other elements of the stigma-induced identity threat model and to understand how these elements interact to influence help-seeking behaviours. A better understanding of the stigma-induced identity threat model will lead to improved rehabilitation services that address individual needs.

The stigma-induced identity threat model seems to be a useful compliment to individual programming presently being offered to clients. For example, recall that stress is the foundation on which the stigma-induced identity threat model is constructed. Stress provides rehabilitative audiologists with a solid theoretical base on which to plan rehabilitative options for specific clients. Within rehabilitative audiology, several authors have proposed treatments that focus on stress reduction (Jennings, 1993, 2005; Trychin, 1986). Many hearing health care professionals presently assess their client's coping resources to manage the challenges associated with hearing loss. The stigma-induced identity threat model provides clinical audiologists with a rationale for these programs specific to the context of stigma. We expect that this framework will assist audiologists plan a logical sequence of interventions for clients that might experience stigmatization because of hearing loss.

A pertinent illustration of how this model compliments existing audiologic rehabilitation interventions can be seen by re-examining the normalization process described by Hétu (1996). Recall that Hétu proposed a two-step normalization process, whereby people who have hearing loss learn to overcome the detrimental impacts of stigma. In the first step, individuals who have hearing loss (and have experienced the negative emotions associated with communication breakdowns) congregate to start the process of restoring a normal social identity. In the second step, participants return to familiar activities with people who do not have a hearing loss, where they are encouraged to utilize appropriate communication strategies to rebuild confidence in their own abilities to communicate effectively, and to restore a positive self-image.

It is relatively easy to see how the stigma-induced identity threat model compliments the normalization process. In the first step individuals who have the same stigmatizable attribute (i.e., *personal characteristic*) work to improve communication strategies such as assertive behaviours and listening skills, learn to be empathetic to one another and to respond with understanding (i.e. *volitional responses*) to communication breakdowns. The group members are less likely to devalue the social identities of those present (i.e., *identity threats*), thus lowering perceived identity threat. Peer group involvement of this kind likely bolsters self-esteem and confidence (i.e., *outcomes*) of group members. In the second step, after the individual has developed confidence in the application of these strategies he or she is encouraged to test these newly acquired skills in "real-world" settings (i.e., *situational cues*) where they might experience people who ascribe to prejudicial attitudes (i.e. *collective representations*). We expect that when placed against a comprehensive framework of stigmatization (i.e., the stigma-induced identity threat model) clinicians are likely to view existing programs with a renewed sense of direction. From the perspective of audiologists, the stigma-induced identity threat model has the potential to provide insight into stigma relevant problems of help-seeking, adherence (or nonadherence) to hearing health care recommendations and to designing effective programs of assessment and intervention.

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# Chapter Two: Methodology

# Chapter Two: Methodology

The objective of this chapter is to provide an overview of the methodological protocols employed for this dissertation. This section begins with an introduction to the qualitative description approach and a rationale for its selection for the two studies presented herein. That is followed by a description and rationale for the sampling strategies, data collection protocols and analysis techniques employed for the two studies. Finally, the efforts employed to maximize rigor of these two studies are presented. Thorough descriptions of methods employed in these studies are provided in Chapters Three and Four.

## Qualitative description

In order to understand how stigmatization may impact individuals with hearing loss, a qualitative description approach was employed for the two studies included in this dissertation. The objective of qualitative description studies is to provide a comprehensive summary of participant experiences presented in everyday language. Qualitative description studies have been described as "the least encumbered by pre-existing theoretical and philosophical commitments." (Sandelowski, 2000: pp. 337). Qualitative description is based on naturalistic inquiry. Influenced by naturalistic inquiry (Guba & Lincoln, 1989), qualitative description studies allow investigators to observe and learn from participants in their most natural environments. This approach is often used when investigating aspects of health care delivery systems to answer questions such as *Who uses a service?* and *What facilitates or hinders a person to use a service?* (Sandelowski, 2000). The methodologies and procedures employed are chosen in such a way that the participants are totally at ease, as if they were not actually under investigation.

## Personal beliefs and characteristics that shaped methodological design

This research was influenced by the philosophical perspective of "symbolic interactionism" (Blumer, 1969). According to this perspective, behaviours are founded in the meanings that individuals attribute to "objects" (people, events) in the world. Blumer hypothesized that humans are not purely reflexive. Human behaviours are, at least in part based on the *meanings* attributed to things. Meanings arise out of social interactions with other people. Modifications to meanings are made through personal interpretations. According to this perspective, meanings arise through social interactions with others, and are mediated through interpretive processes (Bogdan & Biklen, 1998).

Accordingly, use of qualitative description was influenced by a constructivist approach to inquiry. From this perspective, knowledge arises out of a shared social construction (Berger & Luckmann, 1966). These studies were approached with the belief that experiences and events can exist and take place, but meaning is constructed when experiences and events are perceived by other people (Crotty, 1998). In accordance with this perspective, the studies presented herein were approached with the belief that the participant and investigator share the research experience. The researcher enters into this activity as a reflexive entity, and an understanding that investigators impact the entire research process.

Thus, the execution of these studies was influenced by the investigator's relevant life experiences, knowledge of the topic of investigation and research aptitudes. Certain methodological decisions were made in light of particular characteristics of the investigator and the integral role that the researcher plays in the implementation of a qualitative description inquiry. For example, for the peer-support group study (Chapter Three), the subject of stigma was still somewhat novel, thus, the entry point to the research process was aided by the Major and O'Brien stigma-induced identity threat framework. In the second study, it was decided to employ photo elicitation to keep the interviews focused on stigmatizing situations that were relevant to the participants.

## Sampling

Researchers who engage in qualitative descriptive studies may select among the purposeful sampling strategies outlined by Patton (2002). A purposeful sampling strategy, whereby researchers intentionally select unusual cases to characterize a phenomenon was employed for the help-seeking study described in Chapter Three. This strategy was used in order to recruit individuals who could comment on help-seeking strategies employed before and after joining a peer-support group.

For the help-seeking study, the inclusion criteria sought out individuals who: spoke and understood English sufficiently well to be able to be an active participant in an in-depth interview that would be conducted entirely in that language; had a hearing loss (PTA ≥ 35 dB HL in the better ear (regardless of whether or not they use hearing aids or any other type of hearing assistive devices); adapted to their hearing loss in adulthood (after 20 years of age); were older than 45 years of age; were members of a peer-support group. The exclusion criteria excused individuals who: had any physical trait that may be considered stigmatizing by the participant (herself or himself) or by a member of the research team. The following is a description of the procedure used to recruit participants for the help-seeking study. The investigators contacted the CHIP (Communicaid for hearing impaired persons), CHHA (Canadian Hard of Hearing Association) and conference organizers of the Hearing Loss Association of America, all peer-support organizations for individuals with hearing loss, and requested their aid in the recruitment of participants. These three organizations agreed to send a recruitment flyer to members through the email. The flyer recommended that individuals contact the PhD candidate by email, if they were interested to learn more about the study, or to arrange to be interviewed.

Similarly, for the workplace study presented in Chapter Four, a purposeful sampling strategy was employed, whereby researchers deliberately participants with varied backgrounds (in this case from a variety of occupations. This strategy was used in order to ease the identification of common patterns of behaviour that appear across a variety of participants. Maximum variation sampling allows the researcher to explore both the frequently occurring as well as the exceptional manifestations of a group of interest across a broad range varied cases (Sandelowski, 1995). The ultimate goal of both of these sampling strategies is to describe cases thought to be information rich for the purposes of the study (Patton, 2002). For the workplace study, the inclusion criteria targeted individuals who: spoke and understood English sufficiently well to be able to be an active participant in an in-depth interview that would be conducted entirely in that language; had a hearing loss (PTA ≥ 35 dB HL in the better ear; regardless of whether or not they use hearing aids or any other type of hearing assistive devices); experienced the onset of their hearing loss in adulthood (after 20 years of age); were between 30 and 70 years of age; held a remunerated job (i.e., work for wages) outside the home for at least 20 hours/week; had at least two colleagues in the workplace (to ensure that there are some communication demands in the work place). The exclusion criteria excused individuals who: had any physical trait that may be considered stigmatizing by the participant (herself or himself) or by a member of the research team. The following is a description of the procedure used to recruit participants. Investigators contacted members of CHIP (Communicaid for hearing impaired persons) and CHHA (Canadian Hard of Hearing Association) peer-support organizations for individuals with hearing loss, and requested their aid in the recruitment of participants. These organizations were invited to provide an advertisement to clients that meet the recruitment (inclusion and exclusion) criteria. In addition, they were asked to post the advertisement in a highly visible place in their office and/or their waiting room. Interested parties were instructed to contact the PhD candidate by email, if they were interested to learn more about the study, or to arrange to be interviewed.

## Data collection

Prior to the start of each interview, prospective respondents were presented a consent form (see Appendices 1 and 2), and their ethical rights were explained verbally. Respondents were provided with as much time needed to ask questions about the study and about their ethical rights.

For the interviews conducted with peer-support group members, efforts were made to conduct the interviews in a comfortable environment where the participants would feel secure, comfortable and at ease discussing the stigma associated with hearing loss. The investigators anticipated that the participants would have this mindset while attending a conference organized for this specific population. Thus, nine of the ten interviews were conducted while respondents attended peer-support group activities (e.g., Hearing Loss Association of America conference). The other interview was conducted in the participant's residence. For the workplace study, the setting of the interviews varied somewhat. In London, Ontario (Canada), interviews were conducted in the Dr. Jennings research lab on the University of Western Ontario campus. Dr. Jennings has made this environment welcoming for her research participants. In Montreal, Quebec (Canada), several interviews were conducted in the office of Communicaid for Hearing Impaired Persons, where the Ph.D. candidate was engaged as a volunteer. Again, this setting was deemed to be conducive to interviews. As the investigators did not have an office in Ottawa, Ontario (Canada), the participants were given the opportunity to select a setting for the interviews conducted in this city. Some participants decided to be interviewed at home, while others decided that it would be fine to do the interview in the work setting. The researcher explained to all respondents the importance of selecting a comfortable setting for the interview.

For the peer-support group study, the interviews were audio-recorded using a Marantz Cassette Recorder (PMD101). Each participant was assigned a pseudonym to ensure confidentiality. Upon completion of an interview, the appropriate pseudonym was printed on the cassette(s) to ensure that the investigators could identify one tape from another. Verbatim transcriptions were prepared in Microsoft Word using Dragon Naturally speaking, a voice recognition software. This process involved opening a Word file, listening to the audio recording of the interview, and repeating (word for word) what was said for the voice recognition device. These files were each saved using their assigned pseudonym. For the peer-support group study, the interviews were audio-recorded using a digital audio recorder (Olympus LS-10). Audio files were also assigned a pseudonym, transferred to a computer, and verbatim transcriptions were prepared (by a hired transcriptionist) using a SONY Dictator/Transcriber (Model BI-85).

For both studies, the primary data collection method was in-depth interviews. Consistent with the qualitative description data collection techniques outlined by Sandelowski (2000), the interviewer prepared open-ended questions for the interviews. The first author conducted all of the semi-structured audio-recorded interviews. The format of the interviews was informal, much like a conversation. As a research topic, stigmatization is a sensitive issue for most people with an acquired hearing loss. The interviews started with general questions about the onset of hearing loss and workplace situations. When information about stigma (stereotypes, prejudice or discrimination) was provided by the respondent, more direct follow-up questions were posed. The interviews continued until both investigator and participant were confident that everything about the interview topic had been discussed. During all interviews the investigator took notes to add a contextual account to the interview transcripts. The length of the interviews ranged from 54 to 107 minutes.

As discussed in Chapter Four, an adapted form of photo elicitation was employed for the workplace study. This is a qualitative interviewing technique whereby the interviewer presents a series of images to the interviewee with the intent of provoking a response, evoking memories and extracting information (Clark-Ibanez, 2004; Heisley & Levy, 1991). The participants in the workplace study also complete a workplace questionnaire (see Appendix 3). The questionnaire was used to collect information about each participant's workplace setting in order to provide the researchers with a perspective on participant narratives, and to help the interviewer pose relevant questions about revealing (concealing) hearing loss in workplace settings.

For both studies verbatim transcripts of the interviews were prepared. Within the transcripts, all proper names were assigned pseudonyms and other identifiers were removed to ensure confidentiality. A condensed description of how the text was analyzed is presented below.

## Data analysis and presentation

Content analysis was employed for articles two and three presented in Chapters Three and Four respectively. The objective of content analysis to summarize text based data (Elo & Kyngas, 2008). Sandelowski (2000) suggested that content analysis is an appropriate methodology for qualitative description studies. The purpose of the investigation presented in Chapter Three was to better understand the lived experience of individuals with acquired hearing loss as they relate to stigma and seeking health care. The sole research question for this exploratory study was *How does the stigma associated with* *hearing loss influence rehabilitation help seeking?*. The purpose of the investigation presented in Chapter Four was to better understand the lived experience of individuals with acquired hearing loss as they relate to stigma and interactions with others in the workplace. The sole research question for this exploratory study was *What factors lead individuals to conceal or disclose their hearing loss in the workplace?*

As described in Chapters Three and Four, content analysis (Elo & Kyngas, 2008) has three general steps: open coding, creating categories, and abstraction. During open coding, the researcher reads through interview transcripts searching for text that answers the fundamental research questions. For example, for the peer-support study, open coding involved searching for information that answered the fundamental research question *"How does the stigma associated with hearing loss influence rehabilitation help seeking?"*. When relevant excerpts were discovered, the text was highlighted and assigned a "heading" in the margin of the transcript. The headings were reviewed, and categories of headings were created. The final step of content analysis is abstraction, when investigators prepare general descriptors of the data. In both studies, abstraction was aided by the use of ATLAS-ti (Scientific Software Development Inc., 2004), a software program designed to aid in the organization and analysis of large bodies of text. Using Atlas-ti, meaningful patterns within and across interview transcripts were sought and identified. Data analyses continued until it became evident that extending analyses would produce no new information (Morse & Field, 1995). Most often data collection and analysis are completed in parallel. This approach allowed for a give and take relationship between the data collection and analysis. Insights developed in early analysis were explored in subsequent interviews; similarly, analyses are impacted by recently conducted interviews.

The studies presented in Chapter Three and Four of this dissertation were conducted in general accordance with accepted guidelines for rigor within qualitative research. Willimas and Morrow (2009) provided useful guidelines to evaluate the trustworthiness of qualitative research. These authors described three factors that contribute to research rigor: integrity of the data; a balance between reflexivity and subjectivity; and clear communication of the findings. It is important to note that trustworthiness is influenced by the selected research design. As noted earlier, the starting point for the doctoral candidate was at the constructivist end of the spectrum. Thus, the entry point for the PhD candidate was one that viewed truths as multiple, valued subjectivities of both researchers and participants, and engaged the values of the researcher in the research process.

The integrity of the data was scrutinized in two ways: a concise description of research methods; and sufficient data to support findings (Williams & Murrow, 2009). Related to the first point, efforts were made to fully articulate the research process, in order to allow for replication by future investigators (Patton, 2002). Attempts were made to provide detailed descriptions of all methods and protocols employed by providing rich and detailed methodology sections (Creswell & Miller, 2000; Guba & Lincoln, 1989). To this end, as much as possible (given word limits of selected journals) detailed descriptions of recruitment strategies, interview and transcription procedures, as well as content analysis procedures and inter-coder stability check.

A number of factors influence the sufficiency - quality and quantity - of data collected. In the studies presented herein, a diverse and purposeful sampling of participants was selected to produce rich data and enhance the quality of data. Data quality was also improved by drawing from various data sources. While the primary source of data was interview transcripts, memos were also used as a secondary source of data. Throughout data collection and analysis the PhD candidate wrote detailed memos. These texts comprised an important data source that was considered during data analysis and interpretation. In terms of the quantity of data, we generally subscribed to the accepted guideline that data should be collected until there is a redundancy of data, or until no new information is being revealed. Finally, the integrity of data was influenced by an attempt to honour the voice of participants. An abundant number of quotations were incorporated into manuscripts. For qualitative description studies, where typically a number of themes are described, a sufficient number of quotations means representative quotes for each theme and sub-theme.

Trustworthiness is also influenced by balance between participant perspectives and researcher interpretations. While subjectivity is valued within qualitative research methodologies, and it is important to present the participant perspective, it is also important to monitor the contribution and import given to investigator perspectives. For the studies presented in Chapters Three and Four two strategies were employed in this regard. First, the research team was diligent to verify that all themes arising from analyses were indeed firmly grounded in the interview transcripts, not constructed by investigators. This verification was typically performed by member checking or soliciting respondents to review our findings. "Member checks" of findings and interpretations were conducted by participants, as well as by senior (and) knowledgeable researchers from outside the research team.

The final component of trustworthiness as described by Williams and Murrow (2009) is clear communication of the findings. According to these authors, it is imperative that findings are applied to the relevant social context. In the studies that follow attempts were made to clearly communicate the findings, as well as provide explanations as to why the findings are important. Thus, in addition to the provision of sufficient exemplary interview quotations and investigator interpretations, readers will also find adequate discussion of how these findings fit within social theories, advance our understanding of clinical practice and contribute to relevant literature.

# Chapter Three: Article 2 - Stigma: a negative and a positive influence on help-seeking for adults with acquired hearing loss

# Chapter Three: Article 2 - Stigma: a negative and a positive influence on help-seeking for adults with acquired hearing loss

**Title:** Stigma: a negative and a positive influence on help-seeking for adults with acquired hearing loss

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**Title:** Stigma: a negative and a positive influence on help-seeking for adults with acquired hearing loss

## Abstract

There are stigmas associated with many chronic health conditions that emerge in adulthood. People who present manifestations of hearing loss are often perceived by others to be cognitively diminished, less able and socially incompetent. In order to avoid being identified as a member of a stigmatized group, individuals with hearing loss may choose not to seek health services or fail to comply with recommended treatments. The purpose of this study was to better understand how stigma impacted upon the help-seeking activities of adults with an acquired hearing loss. Ten people who had hearing loss, and were members of peer-support groups participated in audio-recorded semi-structured interviews. Thematic analyses of verbatim transcripts revealed that lasting decisions about hearing loss management were made following "critical junctures", when the negative stress found in the respondent's social and physical environment far outweighed positive energy, or when the positive energy found in the respondent's environment far outweighed the negative stress. The time course development of these processes is described.

Keywords: Acquired hearing loss, stigma, help-seeking, attitudes

## Introduction

Within rehabilitative audiology there are numerous services and programs available to adults with acquired hearing loss. These include (but are not limited to) hearing aid fitting and orientation, counselling with respect to hearing assistance technologies, training in speech perception and conversational skills, communication strategies training and psychosocial adjustment (Gagné & Jennings, 2008). A typical audiologic consultation however does not extend beyond hearing aid fitting and orientation (Jennings, 2005a; Prendergast & Kelley, 2002) and it is estimated that fewer than 25% of adults eligible for hearing aids actually use them (Kochkin, 2007).

In a previous study, Southall Gagné and Leroux (2006) explored the factors that influence the uptake and utilization of hearing assistance technologies among older adults with hearing loss. In that study, we reported that participants delayed help seeking in part due to the stigma associated with hearing loss. Other authors have reported similar delays (in some cases for years) before first contact with a hearing health professional (Brooks, 1979; Kyle, Jones, & Wood, 1985). Moreover, in addition to the impacts that stigma has on technology uptake and use, stigma can also serve as a barrier to prospective users of other audiologic rehabilitation services (Griffing, 1992; Kochkin, 2000b, 2007).

## Definitions

Over the past four decades the understanding of stigma has changed considerably. In 1963, Ervin Goffman defined stigma as *signs or marks that designate the bearer of a spoiled identity*. According to Goffman, people who possessed stigmatizing traits belonged to a social category that brought into question their full humanity (Goffman, 1963). By contrast, the composition of contemporary definitions of stigma reflect attempts by researchers in the social sciences to better understand stigma from the perspective of the person who possesses the stigmatizing trait. Thus, a contemporary definition of stigma is: *the possession of, or belief that one possesses an attribute or characteristic that conveys a social identity that is devalued in a particular social context* (Crocker, Major, & Steele, 1998). For the purpose of this study, we used the latter definition. Further, in the text, *help-seeking behaviours* refers to efforts and attempts made by people with hearing loss to resolve hearing related difficulties through medical, psychological or rehabilitative assistance.

Recent reports indicate that people who possess stigmatizing attributes do not always respond to stigmatizing situations in a uniform manner. In certain circumstances, people are resilient to the negative effects of stigmatization (Shih, 2004). There is thus a variability of individual responses to stigma (Major & O'Brien, 2005). Researchers are now beginning to understand and report the factors that distinguish those who are susceptible to stigma from those that are resilient to stigma. In order to respond to the needs of adults with an acquired hearing loss, a better understanding of the experience of stigma from the *insider's* perspective (i.e., the person who possesses the stigmatizing trait) is necessary (Kochkin, 2007; Major & O'Brien, 2005).

## Stigma-induced identity threat model

In the past ten years, efforts have been made to conceptualize stigma from the perspective of the individual who possesses a stigmatizing attribute. One such conceptualization focuses on *stigma-induced identity threats* (Major & O'Brien, 2005).

Founded on the theories of stress and coping (Lazarus & Folkman, 1984) the stigma-induced identity threat model provides an overview of the individual perception of, and responses to stigmatizing events. When confronted with a potentially stigmatizing situation, the individual who possesses a stigmatizing trait appraises the threat to his or her social identity. If the demands of the situation tax or exceed available personal resources, the event is deemed threatening, thereby creating need for a response. The intensity of a given identity threat is based on the interaction among collective representations, situational cues, and personal characteristics of the individual who possesses the stigmatizing trait. Responses to a threatening event might include non-volitional as well as volitional responses, and there are a variety of outcomes that may arise from a stigma-induced identity threat (Gagné, Southall, & Jennings, 2009; Southall, Gagné, & Jennings, 2009).

One noteworthy characteristic of the stigma-induced identity threat model is that it can account for a range of susceptibility to stigma, as well as a range of responses to stigma. Traditionally, stigma research focussed on the negative effects of stigmatization (Crocker & Quinn, 2000). However stigmatization does not necessarily result in negative outcomes for those who possess the stigmatizing attribute (Miller & Major, 2000). In her article on this topic, Margaret Shih (2004) explored the factors that enable some people to overcome stigma. The author proposed three psychological processes that people might employ to overcome the negative consequences of being stigmatized. First, people *compensate* for stigmas by developing (enhancing) self-protective techniques, such as assertiveness, social interaction skills or through actions undertaken to disconfirm a stereotype. Second, people *strategically interpret their social environment* (e.g., deny or down-play stigma) or *make favourable comparisons* of their own situation to people whom they perceive to be worse off. These strategies are employed to preserve their own self-worth. Finally, people *rely upon alternate social identities* in order to protect themselves from prejudicial attitudes. Individuals have been suggested to possess more than one identity (Hewstone, Hassebrauck, Wirth, & Waenke, 2000). In a given scenario, one identity might be stigmatized, while another identity may not be stigmatized (Crocker & Quinn, 2000; Dovidio, Major, & Crocker, 2000). Some people avoid the negative consequences of stigmatization by identity switching, whereby they select an identity that emphasizes self attributes that are socially acceptable, while down-playing attributes that are stigmatized (Ambady, Shih, Kim, & Pittinsky, 2001).

Shih (2004) also summarized a model of empowerment (Oyserman & Swim, 2001) that might be used to overcome stigma. According to this model, when confronted by stigmatization, some people respond as dynamic beings seeking positive outcomes. Some people actively seek out opportunities to learn a skill so that they might better function in society (Corrigan & Penn, 1999). Other people join peer-support groups for people who possess similar stigmatizing traits (Frable, Platt, & Hoey, 1998; Goffman, 1963; Hétu, 1996). The positive effects of peer-support groups, including reductions in feelings of isolation have been reported for numerous health related conditions (Dunn, Steginga, Rosoman, & Millichap, 2003; Marino, Simoni, & Silverstein, 2007; Whittemore, Rankin, Callahan, Leder, & Carroll, 2000) including people with hearing loss (Hétu, 1996). All of these activities are thought to be empowering (Shih, 2004). In the following section we provide a brief overview of the literature surrounding the stigma associated with hearing loss.

## The stigma associated with hearing loss acquired in adulthood

Evidence suggests that <u>stereotypes</u> (i.e., collective representations) deter many people with hearing loss from seeking audiologic rehabilitation services. Hearing loss is generally thought of as an impairment that primarily impacts older adults (Erler &

Garstecki, 2002; Heine & Browning, 2002a). Prevalence of hearing loss increases significantly with age, such that approximately 33% of people over 70 years of age are thought to have some degree of hearing loss (Davis, 1997). Many of the biological and physiological changes that accompany aging are not valued in Western societies. Thus, it stands to reason that a person who shows signs of hearing difficulties might fear stigmatization based on ageist stereotypes (Coleman, 1997; Espmark & Scherman, 2003). People who have hearing loss are also sometimes thought to be less able, cognitively diminished and uninteresting communication partners (Heine & Browning, 2002b; Kochkin, 2007; Parette & Scherer, 2004). Many people with hearing loss choose not to use hearing aids, because hearing aids make them feel weak, old and disabled (Kochkin, 2007). Goffman (1963) proposed that adaptive technologies such as hearing aids can transmit negative social information and trigger prejudicial attitudes in communication partners. People who use hearing aids are often perceived negatively by communication partners in social settings (Blood, Blood, & Danhauer, 1977; Blood, 1997; Blood & Blood, 1999; Doggett, Stein, & Gans, 1998; Johnson, 1982; Kochkin, 1993). Stigma is regularly cited among the most important barriers to hearing aid use (Griffing, 1992; Kochkin, 1993, 2000a, 2007). In general, people with an acquired hearing loss fear association with negative stereotypes, and this serves as a psychological and social barrier to rehabilitation (Doggett, et al., 1998; Erler & Garstecki, 2002; Gagné, et al., 2009; Hétu, 1996; Jackler, 2006; Jennings, 2005b; Kochkin, 1993, 1994, 2007).

Personal factors (i.e., at the level of the individual) also influence the management of hearing loss. The approach that one takes to help-seeking might be influenced by gender (Garstecki & Erler, 1999), age (Kochkin, 1993), level of self-esteem (Gleitman, Goldstein, & Binnie, 1993), perception of disability (Brooks & Hallam, 1998), and level of confidence (Gatehouse, 1991). For example, Erler and Garstecki (2002) studied women's perceptions of stigma related to hearing loss and hearing aid use across three (adult) age-groups. They found that hearing difficulties and hearing aid use are stigmatizing, but (relative to the two other age groups) less so for women of retirement age.

Reports are also beginning to document how perceived stigma (stigma consciousness) might influence the management of varied health conditions (Funderburk, McCormick, & Austin, 2007; Kinsler, Wong, Sayles, Davis, & Cunningham, 2007; Slade, O'Neill, Simpson, & Lashen, 2007; Tsutsumi, et al., 2007). Although this is an active area of stigma research, more work needs to be done to understand how stigma influences management of health conditions.

<u>Responses</u> to stigmatization also affect the propensity to seek help for hearing difficulties. Stereotypes about hearing loss can strain social exchanges and often lead to avoidance tendencies (Hallberg & Barrenas, 1995; Hallberg & Jansson, 1996). Hétu (1996) described how people with an acquired hearing loss often concealed hearing difficulties and were reluctant to acknowledge hearing loss in some social settings. These responses to the onset of hearing loss serve as an obstacle to help seeking. Alternatively, by acknowledging hearing loss to other people, one derives an emotional release that is beneficial and perhaps necessary before one might contact a health care professional (Danermark, 1998).

The gradual onset and progression of a typical acquired hearing loss is likely an important obstacle to help seeking. Acquired hearing loss evolves gradually over time (Ross, 2000). It is therefore difficult for some people with hearing impairment to identify decline in their hearing ability, and this might serve to delay help-seeking (Garstecki, 1990; Gilhome Herbst, Meredith, & Stephens, 1990). *Acceptance* of hearing loss into one’s self/social identity is likely an important antecedent to an individual seeking help

(Goffman, 1963; Hallberg & Jansson, 1996; Hétu, 1996). Hallberg and Jansson (1996) reported that (over time) some people move in and out of denial and acceptance of hearing loss. These authors found that some women with noise-induced hearing loss fluctuated between a state of hopelessness and a state of accepting their hearing loss.

This (albeit brief) review of stigma and help seeking indicates that (for some people) stigma still serves as an obstacle to the management of an acquired hearing loss. Yet, there continues to be a paucity of research that addresses perceived stigma and help seeking. The purpose of this study was to better understand the lived experience of individuals with acquired hearing loss as they relate to stigma and seeking health care.

## Methodology

A qualitative description research design (Sandelowski, 2000) was selected to explore the research question how does stigma influence the help seeking activities of adults with acquired hearing loss. The objective of qualitative description studies is to provide a comprehensive summary of participant experiences presented in everyday language. Influenced by naturalistic inquiry (Guba & Lincoln, 1989), qualitative description studies allow investigators to observe and learn from participants in their most natural environments. This approach is often used when investigating aspects of health care delivery systems to answer questions such as *Who uses a service?* and *What facilitates or hinders a person to use a service?* (Sandelowski, 2000).

A purposeful type sampling was employed for this study. As with any type of purposeful sampling, the ultimate goal is to describe cases thought to be information rich for the purposes of the study (Patton, 2002). For the present study, we deliberately sought to conduct interviews with individuals who had a hearing loss and were members of a peer-support group. We reasoned that these individuals *become* peer-support group members, and therefore have at least two perspectives or viewpoints from which to consider and comment on their life as a person who possesses a stigmatizing attribute (i.e., before and after they sought help for their hearing loss; namely before and after they joined a peer-support group). Two important assumptions were made about the sample of participants. First, it was assumed (as with any chronic impairment) that help-seeking activities of individuals with acquired hearing loss extend beyond first consultation with a hearing health professional. The second assumption is linked to the first. Specifically, it was assumed that for this group of participants, the facilitators, barriers and strategies employed to seek help for hearing difficulties changed over time. These reasons, as well as the aforementioned presupposition that these individuals likely possess more than one perspective on stigma and help seeking, made the investigators confident that a sample of individuals involved in peer-support groups would provide information rich interviews, and satisfactorily answer the sole research question: *How does the stigma associated with hearing loss influence rehabilitation help seeking?*

Ten individuals participated in the study (M=3, F=7). The average age of the participants was 65 years, with an age range from 55 to 76 years (sd=7.91). All ten participants had an acquired hearing loss that was progressive in nature. Some variation existed in the age of onset of hearing loss: six participants had an adult onset of hearing loss, three participants had a hearing loss that started in middle childhood, whereby recognition of hearing difficulties and subsequent help-seeking started in adulthood; and one participant reported a childhood onset of hearing loss that was diagnosed and treated in adolescence. Eight of the 10 respondents reported to have an audiometrically profound hearing loss, while two participants indicated that they had no residual hearing.

As a group, the participants were considered to be very knowledgeable of technological aspects of rehabilitative options available to people who have an acquired hearing loss. The participants reported use of hearing aids for an average of 27 years and hearing assistance technologies for an average of 18 years. All participants were members of a peer-support group for people with hearing loss at the time of their respective interview. Among the participants, involvement in the peer-support groups ranged from periodically attending group meetings to National / International group representative.

Attempts were made to conduct the interviews in comfortable settings. Many interviews were carried out while respondents attended peer-support group activities (e.g., Hearing Loss Association of America conference). By request, one interview was conducted in a participant's residence. The investigators anticipated that the participants would feel comfortable discussing the stigma associated with hearing loss while attending activities organized for this specific population. The fact that the vast majority of the interviews were conducted in these types of settings therefore served to authenticate the data, as a discussion of hearing loss stigma would likely be more openly articulated while in the context of an event organized for a group of people who all possess the same stigmatizing trait (i.e., hearing loss), and in a relative absence of people who hold prejudicial attitudes.

The first author (KES) conducted all of the semi-structured audio-recorded interviews. KES had training in qualitative interviewing and through years of volunteer work with community groups devoted to serve individuals with hearing loss, the necessary skills to interact with hard of hearing participants. As a preamble to the interviews, the participants were told that the investigators were interested in learning more about their attempts to seek help for hearing difficulties and situations in which prejudicial attitudes about hearing loss influenced their help-seeking. The format of the interviews was informal, much like a conversation. The interview guide (see Table 1: Interview guide) was designed to produce a detailed account of the participant's efforts to seek help for hearing difficulties, and a description of how stigma might have influenced these efforts.

Table 1: Interview guide

1. Describe for me the time leading up to the onset of hearing loss.
2. What lead you to seek help from hearing health professionals?
3. What has hindered you from seeking help?
4. What has facilitated help seeking?
5. What motivated you to become involved with a peer support group?

As a research topic, stigmatization is a sensitive issue for most people with an acquired hearing loss. Therefore, we started the interviews with relatively easy (i.e., broad) questions about the onset of hearing loss and initial efforts to seek help. When information about stigma (stereotypes, prejudice or discrimination) was provided by the respondent, more direct follow-up questions were posed in order to identify how stigma might have influenced help seeking. The investigators recognized that there was a risk that some respondents might revert to proverbial information learned at peer-support groups, rather than providing information concerning personal experience. The interviewer was therefore diligent in seeking narratives of a personal nature. The interviewer was well versed in the educational materials produced and circulated by peer-support group organizations, was adept at identifying these narratives, and redirecting the interview back to the respondent's own experiences and opinions.

Verbatim interview transcripts were analyzed using thematic analysis. Thematic analysis, such as the procedure outlined by Elo and Kyngas (2008) is appropriate when there is limited knowledge about a research topic (Hsieh & Shannon, 2005). This data-driven approach to content analysis is entered into without any pre-conceived theoretical assumptions. The first author read line by line through hardcopies of the interviews, searching for text that answered the research question. Relevant text was highlighted and assigned a meaningful label (Huberman & Miles, 1994). For example, if a respondent indicated that they did not want to obtain hearing aids because only old people use hearing aids, this section of text might be labelled "ageism". This process is known as coding. The first author coded text line-by-line, gradually working through all of the interview transcripts. The objective of this task is to ensure that all text that addressed the basic question be assigned a code. Once all of the transcripts had been coded a first time, the code list represented a preliminary coding schema. Next, the transcripts were re-read several times, scrutinizing the content of the text, while making adjustments to the coding scheme. Typical adjustments made during this process included creating categories of codes that characterized related opinions or experiences (Patton, 2002). For example, a category might be created for all of the stereotypes associated with hearing loss, and named "stereotypes". In parallel to the coding process, a codes-definitions-exemplars table (see Appendix 4) was prepared (and when needed, adjusted) so that all investigators understood what each code and category represented. Re-reading the interview transcripts and scrutinizing the content of the coding schema continued until no additional adjustments based on content were deemed necessary.

The next step of content analysis (Elo & Kyngas, 2008) is to test the dependability the application of codes. The reliability of the list of codes was established by comparing how the first author coded a ten-page section of text with how an individual from outside the research team coded the same text. To complete this task, we enlisted a colleague from outside of the field of audiologic rehabilitation to code a randomly selected excerpt from one interview. This colleague, who worked in a different health field had an understanding of the psycho-social impacts of sensory disabilities, had previously coded qualitative interviews and was provided with the most up to date version of the codes-definitions-exemplars table to aid in the assigning of codes. The dependability of the application of codes was established by calculating the number of passages similarly coded, divided by the total number of coded passages. An acceptable reliability score of 0.8 (van der Maren, 1996) was established on the first attempt.

The interviews were then uploaded into ATLAS-ti (2004) a software program designed to aid in the analysis of large bodies of text. Computer programs such as ATLAS-ti provide an interface to organize and manage interview transcripts, to quickly move from one section of coded text to another and to examine how code categories potentially relate with one another. During this phase of content analysis, meaningful patterns (i.e., themes) within and across interview transcripts are sought by identifying how often categories appear together, before or after another in the text (Morse & Field, 1995). It bears repeating that software programs such as ATLAS-ti are *data management* tools. It is the researcher's responsibility to determine what is and what is not relevant, and under which category to place the relevant iterations.

An early draft of the manuscript was sent to one respondent to establish that the findings were representative of their experiences. This person agreed with the analyses presented. In addition, a professional in the area of audiologic rehabilitation was recruited to review the manuscript from a theoretical perspective to confirm that the themes in the analysis were reasonable and commonly encountered.

# Results

In the section that follows, three themes that arose from the analysis of the raw data are presented. The three themes are: 1) A gradual build-up of negative stress; 2) Critical Juncture One – mounting losses lead to unmanageable stress and an abrupt intensification of the need to seek help; and 3) Critical Juncture Two – build-up of positive energy initiates involvement in peer-support group and transformation. For each theme, excerpts drawn from the interview transcripts are provided. Directly following each excerpt, in parentheses, we cite the respondent and line number from the respective transcript (e.g., P1: 346). The excerpts presented are representative of patterns across the interviews.

## A gradual build-up of negative stress

The years immediately following the individual's recognition of the onset of hearing loss were characterized by a present and progressive build-up of negative stress. Important factors that contributed to this build-up of stress included, negative societal attitudes about hearing loss, lack of understanding from family, co-workers and friends, frustrations because everyday activities had become more difficult, and not knowing where to turn for help.

Some respondents suggested that *the general public is not well informed about hearing loss*. One participant was of the opinion that the general public does not appreciate the challenges of hearing loss compared with other disabilities. Regularly interacting with people (family, friends and colleagues) who were unable to relate to the challenges posed by hearing loss acted as a barrier to people with hearing loss seeking help.

*"There is something noble about being blind and coping. Mobility impaired and coping. Hearing impaired? What are you whining about?" (P6: 556)*

The respondents described how elements found in their immediate *social environment* made it difficult for them to seek help for hearing difficulties. Some respondents spoke of maladaptive attitudes present within their own family that acted as a barrier to help seeking.

*"I had a grandmother who was from Vienna, not even first-generation, who said, she herself was deaf, and said, " I will be in my grave before I let my granddaughter wear hearing aids." (P2:42)*

Most participants stated that they *denied hearing difficulties* and did not seek help in the years following the initial onset of hearing loss. Concealing their hearing loss was simply easier than explaining it to people who might not understand.

*"[I went] through that denial. "There is nothing wrong with my hearing".. and fighting it because you do not want to be hard of hearing. You may accept that you have to do other things in your life but you do not want to be hard of hearing, because of the stigma." (P4: 546)*

Many of participants expressed that people who acquire hearing loss in adulthood *do not have access to adequate information* in order to make informed decisions regarding audiologic rehabilitation.

*"My family has a 40 or 50 year record of hearing loss. None of us had ever been directed toward any support networks or any assistive devices or anything." (P11:96)*

Related to the idea that respondents lacked access to the necessary information, many respondents viewed hearing health professionals as a barrier to help seeking.

*"I think maybe all audiologists ... Doctors need to listen to simulated hearing loss to realise what their patients are going through." (P9:580)*

The respondents characterized the years following initial onset of hearing loss as a time of stress and frustration. This stress was in part due to societal attitudes concerning hearing loss, and in part due to their own beliefs about hearing loss. Most respondents stated that they lacked the direction and resources to seek help during this time in their life.

## Critical Juncture One – mounting losses lead to unmanageable stress and an abrupt intensification of the need to seek help

Untreated hearing loss resulted in situations of stigmatization and participatory *losses* that ultimately lead to *unmanageable stress and an abrupt intensification of the need to seek help*. We referred to this climax of negative stress as *Critical Juncture One*. For the purpose of this manuscript, the term *loss* might be thought of as a valued social, vocational or leisure pursuit put in jeopardy (or conceded) due to the inability to adaptively respond to the stigma associated with hearing loss. It is important to note that most respondents experienced multiple and concurrent losses, both related to and unrelated to hearing difficulties. The description of this theme is divided into two sections: a) mounting losses; and b) unmanageable stress and an abrupt intensification of the need to seek help.

### Mounting losses

Many participants described *losses experienced in their social life*. The respondents explained that the quantity and quality of social exchanges deteriorated because of their hearing difficulties. One respondent expressed resentment and anger because her friendships and family relations had changed for the worse.

*"I can't talk to my children the same way I could before. They hate that. I hate it also. But we try to [work it out]... So with them, we try to communicate in other ways. That is a simple one to identify…My circle of friends. My good friends are still my good friends. But the relationship changes there also. You have to rebalance..." (P12: 467)*

The vast majority of respondents described *losses that they experienced in the workplace*. Several respondents described uncomfortable situations when they were pressured or bullied at work. For example, the boss of one respondent responded threateningly when she asked if she could use an adaptive aid with her workplace telephone.

*"I remember that boss. I can still see his face as if it were yesterday. He was a tall son of a [swear word]. He said, "No. You can't fool around with Crown property. You can't do that. And if you can't do the job we will just demote you and put you somewhere else." (P8: 125)*

Most participants described negative actions such as being terminated, demoted or being asked to give up work-related duties because of hearing problems.

*"[Work] was such a strain that I went home with a migraine everyday. Everyday. By March of that year, I went to [my boss] and said that I couldn't do it anymore. He said, "Take sick leave. You have two years. And then decide after that." Well my hearing didn't get any better." (P6: 276)*

For some respondents, the discrimination experienced in the workplace resulted in stigmatization.

*"That was a very disturbing experience, because it was the first time that it was rammed home to me that I had become incapable. I had become incompetent under certain circumstances. (P1:138)*

The participants also described the *emotional impacts of these losses*. One person described the emotions she felt after being forced to go on disability insurance.

*"I was the kind of kid who was raised to believe that I couldn't miss a day of school. You had to be on your deathbed before you would not go to school or work. And suddenly here I was on disability and the only thing wrong with me was that I was hearing impaired. I was a goldbricker in my head. I felt like I was just cheating and if I work harder at it I should be able to still do that job even though I would be in tears at the end of the day because I couldn't hear on the phone." (P11: 221)*

That same person described how she did not feel as though there was anyone who could relate to the problems she was having at work (and in her personal life).

*"I really thought I was the only person like me. I didn't know that there were thousands and thousands of mes out there who are feeling the same isolation, the same sadness, the same frustration, the same anger, the same " what do I do about this?" type feeling." (P11: 314)*

## Unmanageable stress and an abrupt intensification of the need to seek help

Mounting losses precipitated a Critical Juncture of profound stress when many respondents claimed that they hit rock bottom. This experience served to trigger help seeking. Although the psychosocial consequences associated with hearing loss played a primary role in inducing Critical Juncture One, personal difficulties apart from communication problems also contributed. For example, two respondents described how the negative effects of hearing problems in the workplace combined with other major life stressors to induce Critical Juncture One.

*“I was making myself physically ill. And my blood pressure was going off the charts. I was gaining weight. All physical manifestations from the stress of hearing loss. But I had never put them together. I didn't realise that it wasn't my fault. 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. I was seriously like lying in bed and not being able to get up in the morning. And I reached out and got some psychological counselling and decided what I needed to do was to work with a life coach and decide what I wanted to do with the rest of my life.” (P11: 234)*

Another respondent described her Critical Juncture One.

*“My migraines were getting worse. I said,”What do I do? I am only 55. You mean to say that I have to go on disability right away? If I go on disability I only get 70% of my pay.” And my marriage was pretty well on the rocks by then. I was in debt. I can't retire. And I can’t go on disability. “What do I do? I am kind of at a crossroads here.” And I had some heavy decisions to make.” ... I think that God works in funny ways…he makes you go through these things so that you can build yourself up, so that when things like this happen you are going to end up on top.” (P8: 857)*

It is important to note that the negative experiences recounted by participants were most often one short chapter in a long (and truly inspiring) story. These two women insisted that hitting bottom enabled them to make positive changes in the way that they managed their hearing loss.

## Critical Juncture Two – build-up of positive energy initiates involvement in peer-support group and transformation

The respondents described this as a time when an increasing number of positive influences entered and affected their lives. We referred to this time as a C*ritical Juncture Two*. The respondents spoke of the sense of community and of a long sought after sense of social belonging they derived from involvement in peer-support groups. The participants explained that involvement in these groups facilitated the development of new and healthy attitudes about (their own) hearing loss. This social support enabled many respondents to seek out services without feeling stigmatized. A common sentiment expressed was a desire to affect positive change so that other people with hearing loss might steer clear of the negative experiences that they had endured.

For many respondents, important losses incurred earlier were transformed into activities or projects that they engaged in with the peer-support group. For example, one respondent who had previously characterized herself as unintelligent and lazy, now through her involvement in the peer-support group had the opportunity to act as an instructor, whom people turned to for wisdom. She explained that this activity made up for the losses that she experienced earlier in life.

*"I had this passion in me… I think that* [one event she organized] *was a main turning point, because the person who got up on that stage that day, I think that she almost did a reincarnation that day. She believed in her passion.* [ She started to cry] *I still can't believe that sometimes. It really is something very special to me. At the end of the day when we were closing up and people were saying how grateful and happy they were and how confident that they were that we would be able to change* [her work setting]*, I am standing there, thinking. This poor little girl* [talking about herself] *who wouldn't believe in*

*anything. You were too stupid and lazy. You were able to create this. Pretty damn special….that day […] it was just flowing out of me." (P8: 1130)*

Another respondent, who experienced losses in her work life due to a lack of technological accommodations, worked to eliminate this type of discrimination. As was often the case, the nature of her involvement in this activity was consistent with the personal strengths that she possessed prior to the onset of the hearing loss. This participant repeatedly emphasized that she personally needed and benefited from working within groups. She now experienced similar benefits with peer-support groups.

*"I felt that it was a good time for me to make* [professional] *changes, although there is always this thread of sadness and resentment and anger about the hearing loss. There is always this other thought included that if I didn't have this hearing loss I could continue doing the work that I love until I drop. For another 25 years. A lot of the people in my profession continue working until quite an old age."* [and later regarding her activities within the peer-support group]*"It is a very selfish thing in a sense, but it is part of me also to [work] in the helping professions. That is what they are called. But whatever life work you choose, you are choosing to meet your own needs, hopefully. Whatever that happens to be. So, paying attention to the hearing loss the way that I am choosing to do it,* [edited to ensure confidentiality] *that helps me so much. It helps me to continue things that are important to me in my life." (P12: 456)*

A final respondent described how lost friendships were replaced by a profound sense of belonging through her involvement with her peer-support group. She explained that her search for a support group was a conscious attempt to replace lost friendships. She sought out new friends who would understand her hearing loss.

*"I was very much looking for new friendships. But I wanted friendships with*

*people who would understand, that I wouldn't have to constantly explain it to them. .... I really didn't want to go out into the hearing world, but I wanted friendships and companionship. I wanted someone who I could go to the movie with. Or have dinner with. So these people that I found in the* [mentioned a specific chapter of a peer-support group association] *chapter were it." (P11: 232)*

Most respondents referred to a sense of belonging they experienced when engaging in peer-support group activities. These activities provided a surge of positive energy and life direction.

*"It's like the first time I went to Israel. I didn't have to be a Jew, I was in the majority not the minority. There was a similar kind of emotional, intellectual, actual physical feeling." (P3:99)*

[Peer-support groups]*"... are very special to me... You feel like you are talking to someone who understands and you also start to replace some of the things that you have lost. In terms of social networks by joining these groups, I think...Because of that one party, the amount of understanding and the immediate replacement of some kind of social interaction where you don't feel shy or excluded... From that day, I knew that I had to be involved in that kind of thing." (P12: 362)*

The respondents also described an obligation "to give back". For many, this duty meant that whenever possible, to pass on knowledge about communication strategies and rehabilitation services.

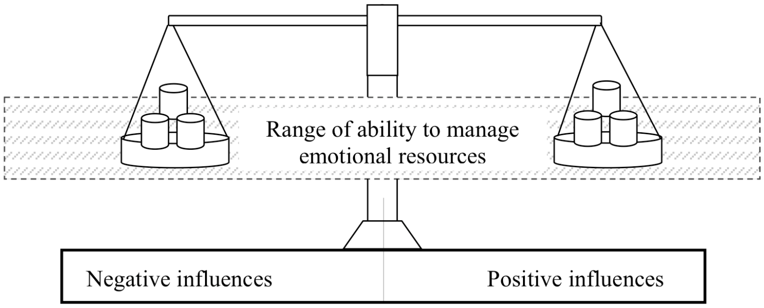
*"....so that this person will never have to live through discrimination, the feeling of being alone, and not knowing where to turn for help."*

The respondents described a need to educate the public about the challenges frequently encountered by people who have a hearing loss. Many participants claimed that it is only through education campaigns that stereotypes will be destroyed.

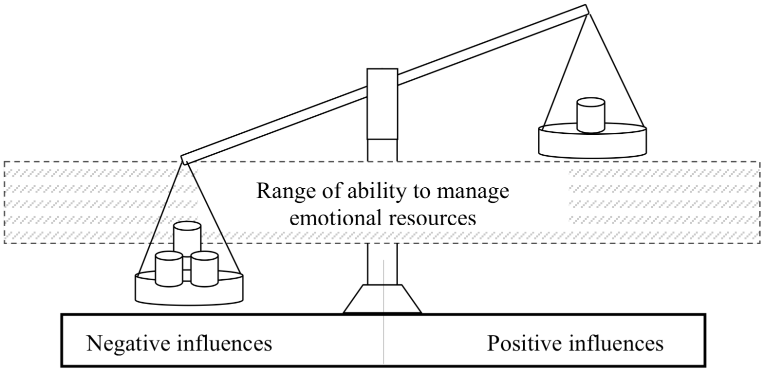
## Discussion

In this section a series of graphic representations are proposed that depict how positive and negative influences found in the respondent's social and physical environment influenced help seeking (see Figure 1). We propose that these positive and negative elements were cumulative, such that the interaction of positive energy and negative stress (associated with hearing loss stigma) may be conceived of as a set of scales. Onto these scales are placed resources, when maladaptive, they come in the form of negative stress; when adaptive, they come in the form of positive energy. Like a scale, the resources assigned to one side of the scale offset or counterbalance the opposing side.

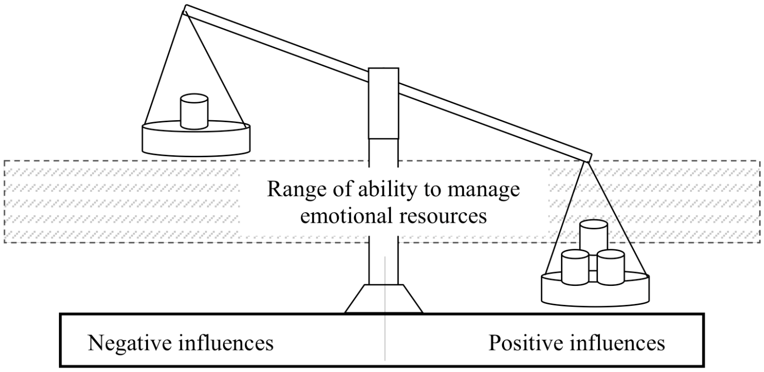
In most instances, participants in this study existed within a range of ability to manage their emotional resources (i.e., positive and negative resources offset each other) in such a way that resulted in a relative equilibrium in the respondent's life. However, as the analyses revealed, most respondents experienced a heightened propensity to seek help during two Critical Junctures, when negative stress and positive energy were out of balance: 1) a time when negative stress far outweighed positive energy (i.e., C*ritical Juncture One)*; and 2) a time when positive energy far outweighed negative stress (i.e., C*ritical juncture Two*).



Person in relative state of equilibrium



Person at threshold of Critical Juncture 1



Person at threshold of Critical Juncture 2

Figure 1: Representative scales

**Figure 1 caption**

*Figure 1 legend: Scales depict the balance of positive energy and negative stress as experienced by respondents. Negative influences are placed on left side of the scale. Positive influences are placed on right side of scale. The shaded portion across the middle range of each scale represents the respondent's ability to manage emotional resources. The top scale configuration depicts the balance between positive and negative influences that might result in a person experiencing relative state of equilibrium. The middle scale configuration depicts the imbalance between positive and negative influences that might result in a person experiencing a "Critical Juncture One". The bottom scale configuration depicts the imbalance between positive and negative influences that might result in a person experiencing a "Critical Juncture Two". It is assumed that there are innumerable combinations of positive and negative influences, thus, there is the possibility of innumerable scale configurations.*

It is important to note that the scales analogy is largely coherent with the stigma-induced identity threat model described earlier. As Major and O'Brien (2005) described, cues inherent to a stigmatizing situation, characteristics of the individual who possesses the stigmatized trait, and the nature of the stereotype all contribute to an identity threat appraisal. According to this conceptualization, when a person is confronted by a stigmatizing event, should the *negative* demands of the situation exceed the individual's resources, a coping response might be triggered. Analyses conducted for this study indicate that an excess of *positive energy* might also induce responses. In the paragraphs that follow, a more detailed description of the scales analogy is presented.

The top scale configuration represents a time in the respondent's life when, notwithstanding the hearing loss there was a balance between positive and negative influences. Consequently, management of stigma related threats might be more easily dealt with. Recall that in the first theme the respondents experienced a build-up of negative stress associated with participatory losses. One might imagine a scale configuration whereby the "load" assigned to the negative influences marginally outweighs the positive influences, but importantly the load remains within the *range of* *ability to manage emotional resources.* In an instance like this, the respondents may or may not be inclined to seek help, because they still have the emotional resources required to manage.

Critical Juncture One – mounting losses lead to unmanageable stress and an abrupt intensification of the need to seek help. Increases in hearing problems coinciding with increases in stress have been reported by other authors (Hétu, Riverin, Lalande, Getty, & St-Cyr, 1988; Jang, Mortimer, Haley, Chisolm, & Graves, 2002). Most respondents in this study indicated that they went through a phase of denial and concealing following the identification of their hearing loss. These maladaptive coping responses likely contributed to the increased level of stress experienced by the participants. Critical Junctures are significant and noteworthy to the present discussion because they were the times when respondents made lasting decisions and behavioural changes related to help seeking. The status quo was no longer an option. Using the scale metaphor, when respondents were confronted by numerous losses, the negative stressors far outweighed the positive energy. The situation had seemingly become unmanageable, resulting in the triggers or prompters to seek help. Note that the sources of stress that prompted changes in help-seeking behaviours were not limited to hearing loss. Concerns with other aspects of the respondent's life also seemed to contribute to help seeking. Unquestionably, the stress associated with communication difficulties and communication breakdowns was a central topic in the interviews, however other significant life events (care-giving for a loved one, birth of a child, loss of job, death of loved one) regularly coincided with adjustments in management of hearing loss. For this reason, it is proposed that diverse stressors might have a cumulative effect in prompting help seeking. Critical Juncture One seemed to trigger a self-correcting or compensatory build up of positive energy. Following the climax of negative stress, many respondents sought help to better manage the 'overall' difficulties they experienced, including but not limited to hearing loss. This self-initiated act seemed to build confidence and lead to a progressive build-up of positive energy.

The respondents indicated that positive energy came from varied sources found in the respondent's social and physical surroundings. Among other sources, positive energy was obtained from hearing health care professionals, technical accommodations and meeting influential people. Using the scale metaphor, respondents had reached a point when the positive energy far outweighed negative stress and the respondents passed through a Critical Juncture Two when they uncovered the personal resources to join a peer-support group. All respondents described the support, liberation and relief found in peer-support groups. In these groups, respondents learned how to better manage their hearing loss, while new relationships with understanding people eased previously incurred losses. This involvement in some way addressed the losses that were incurred, and invariably lead to important benefits such as confidence, self-esteem and self-efficacy.

From a general perspective, the results of this study support the theoretical orientation that stigmatization can occasionally lead to positive outcomes (Shih, 2004). Specifically, the experiences of the respondents in this study fit well within the model of empowerment proposed by Oyserman and Swim (2001). According to the empowerment model, individuals confronted by stigmatization do not respond as passive targets; rather, they respond as dynamic beings searching for positive outcomes. In the present study, the best example of participants searching for positive outcomes was witnessed following Critical Juncture Two when the respondents chose to become involved with a peer-support group. Most participants chose to volunteer their time with the goal of eliminating the source of previously incurred losses. This finding is typical of the empowerment model in two ways. First, people who possess a stigmatizing attribute are likely to be empowered if they identify with a group of individuals who also possess the stigmatizing trait (Corrigan & Watson, 2002; Frable, et al., 1998). Second, the participants in this study expressed resentment and a desire to eradicate what they perceived to be stigma-related imperfections in service provision. This finding is also consistent with previous research from the area of mental illness stigma (Corrigan & Watson, 2002).

## Limitations

The findings of this study should be considered within the scope of two methodological decisions. First, it is important to note the limitations of retrospective interviewing. These data might therefore be subject to poor recall. Nevertheless, it appears that people with hearing loss who have experienced stigmatizing situations hold on to these memories, and these memories are easily recalled as they tend to be of an emotional nature. Moreover, regardless of the accuracy of the respondent's memories, these are the recollections of events that influence current and future help-seeking behaviours.

Second, it is important to note that the experiences of this sample should not be considered representative of all peer-support group members, let alone all people who acquire hearing loss in adulthood. This comparatively small and homogenous sample was selected in order to provide information rich data relevant to the purpose of the study. All of the participants were exceptional in at least one respect; all of them were involved to some extent in a peer-support group. Obviously, not everybody with a hearing loss, even among those who overcome many of the deleterious effects of stigma participate in peer-support groups.

## Clinical implications

The narratives of the respondents in this study provide some clues of how the balance of positive and negative influences found in one's social and physical environment influence help seeking. In this study we found that the respondent's propensity to seek help was influenced by an interaction of individual traits of the person with hearing loss, the balance of positive influences and negative stress, and influences found in the social and physical environment that influence help-seeking. Clinicians might be well advised to watch for clients who might be heading toward critical junctures. For instance, clinicians should be cognizant of all aspects their client’s life when evaluating the inclination to follow a proposed treatment. Stressful life events apart from hearing difficulties may inspire help seeking. Clinicians are also reminded of the social and emotional benefits of peer-support groups. Hearing health care professionals may find that their clients will respond more positively to recommended rehabilitation services if they also have some level of involvement with a peer-support group.

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# Chapter Four: Article 3 - Factors that influence disclosure of hearing loss in the workplace

# Chapter Four: Article 3 - Factors that influence disclosure of hearing loss in the workplace

**Title:** Factors that influence disclosure of hearing loss in the workplace

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**Title:** Factors that influence disclosure of hearing loss in the workplace

## Abstract

The purpose of the study was to identify the factors that lead individuals to conceal or disclose their hearing loss in the workplace. A qualitative research approach was used to address this issue. Twelve people who had an adult onset hearing loss, and were gainfully employed participated in audio-recorded semi-structured interviews designed to probe issues related to disclosure of hearing loss. The photo elicitation interview technique was employed to generate the most relevant data. Content analyses were used to extract pertinent information from verbatim transcripts. Five recurring themes emerged as important considerations in relation to this topic. The findings are discussed in relation to other concealable stigmatizing traits, sociological models of stigma and social cognitive theory. Clinical implications are explored.

**Key Words:** hearing loss, stigma, work, disclosure, qualitative research, photo elicitation

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# Introduction

Over the years there have been a variety of investigations into the challenges faced by workers with hearing loss. Investigators have studied the employment status (Blanchfield, Feldman, Dunbar, & Gardner, 2001; El-Khiami, 1993; Parving & Christensen, 1993; Schroedel & Geyer, 2000), career development (El-Khiami, 1993; Jarvelin, Maki-Torkko, Sorri, & Rantakallio, 1997; Punch, Hyde, & Power, 2007) and impact that hearing loss has on income and career earnings (Kochkin, 2007; Winn, 2006). Studies have been undertaken to understand occupational hearing loss from the perspective of the worker (Hetu & Getty, 1993; Hétu, Riverin, Lalande, Getty, & St-Cyr, 1988), the worker's family (Hallberg, 1996; Hétu, Lalonde, & Getty, 1987) and from the perspective of the co-workers (Hétu, Getty, & Waridel, 1994). Investigators have examined attitudes held by the general public concerning the employability of adults with hearing loss (Weisel & Cinamon, 2005; Zahn & Kelly, 1995), and have documented the attitudes of the workers themselves with respect to general challenges encountered in the workplace (Barlow, Turner, Hammond, & Gailey, 2007; Hétu, et al., 1988; Punch, et al., 2007). Studies have explored the availability and use of workplace accommodations (Geyer & Schroedel, 1999; Scherich & Mowry, 1997) and use of audiologic and vocational rehabilitation for workers with hearing loss (Getty & Hétu, 1991; Hétu & Getty, 1991; Lalande, Riverin, & Lambert, 1988). In spite of this body of work the challenges facing workers with hearing loss persist. Successful integration of workers with hearing loss into their work setting remains a challenge (Backenroth & Ahlner, 1998; Danermark & Gellerstedt, 2004; Garcia, Laroche, & Barrette, 2002; Hallberg, Passe, & Ringdahl, 2000; Hass-Slavin, McColl, & Pickett, 2005; Laroche, Garcia, & Barette, 2000).

In 2005, the Canadian province of Ontario passed the Accessibility for Ontarians with Disabilities Act, 2005 (Government of Ontario, 2005). In doing so, Ontario became the first Canadian jurisdiction to conceive accessibility standards for people with disabilities. However, as of June 2010, the employment accessibility standard for this legislation was still in proposal format and had not yet been passed into law. While accomplishments such as this are somewhat encouraging, challenges persist. On the one hand, the rights of employees are protected in both Canada and the United States through policies that limit access to medical information only with written informed consent of the worker. Moreover the Americans with Disabilities Act states that a person who applies for a position is not required to disclose a hearing loss to a potential employer. Yet, hearing loss must be disclosed if the applicant needs reasonable accommodation during the hiring process. Also, a potential employer can ask if the applicant has a need for reasonable accommodation (The U.S. Equal Employment Opportunity Commission, 2006). An examination of data compiled by the US Equal Opportunity Commission for the period 1992-2003 revealed that people with hearing loss filed more than 8900 cases of discrimination. Allegations ranged from hiring practices to matters of discharge and reasonable accommodation (Bowe, McMahon, Chang, & Louvi, 2005).

## Workplace challenges confronted by people with hearing loss

As a group, individuals with hearing loss experience comparatively more difficulties finding gainful employment when compared to their normal hearing peers (Blanchfield, et al., 2001; El-Khiami, 1993; Parving & Christensen, 1993; Schroedel & Geyer, 2000). In the United Kingdom, a study conducted by the Royal National Institute for Deaf People[1] (2006) reported a 63% employment rate for working age adults who have hearing loss, compared with 75% for the total UK labour force. The US Bureau of the Census regularly reports similar findings. For example, in 2005 59% of the labour force (i.e., individuals aged 21-64 who are employed or seeking employment) who *find it difficult to hear*

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[1] Although its name implies that they only serve people who are deaf, the Royal National Institute for Deaf People (RNID) website states that they work on behalf people who are both deaf and hard of hearing.

*conversations* were employed, as opposed to 77% percent of the total US labour force (U.S. Census Bureau, 2005).

Numerous authors have reported that the worksite is a <u>challenging psychosocial environment</u> for individuals with hearing loss (Backenroth & Ahlner, 1998; Danermark & Gellerstedt, 2004; Garcia, et al., 2002; Hallberg, et al., 2000; Hass-Slavin, et al., 2005; Laroche, et al., 2000). Workers with hearing loss have been found to experience greater imbalance between job demands (mental workload, psychological requirements or work) and job control (social autonomy in decision making, and breadth of job skills) than workers without hearing loss (Danermark & Gellerstedt, 2004; Gellerstedt & Danermark, 2004; Kramer, Kapteyn, Kuik, & Deeg, 2002). The integration of workers with hearing loss into the workplace may be influenced by the type and size of employer, by the patterns of communication required for the designated job, by the level of support provided to the worker from colleagues and supervisor, by the availability of accommodations in the designated work area, and by personal coping styles of the person with hearing loss (Rehabilitation Research and Training Center for Persons who are Deaf or Hard of Hearing, 2005). The RNID (2006) found that 55% of respondents experienced social isolation, while 24% of respondents reported difficulties communicating with their colleagues.

There is also evidence that hearing loss may have <u>negative impacts upon employment transition and career development</u> (El-Khiami, 1993; Jarvelin, et al., 1997; Punch, et al., 2007). In the RNID study (2006), approximately half of the respondents reported that they were denied promotion and career advancement due to their hearing impairment. Being denied employment and promotion has obvious ramifications on employment income. In the United States it was estimated that yearly household income, where one inhabitant had hearing loss was approximately $12, 000 (US dollars) lower per year, depending on the severity of hearing loss (Kochkin, 2007). This disparity was halved when the person with hearing loss obtained appropriate rehabilitative technology and services. Similarly, Capella (2003) reported that individuals with hearing loss earn 17% less than people with normal hearing.

## Accommodations for workers who have hearing loss

Various accommodations can be made for workers with hearing loss (Geyer & Schroedel, 1999). The use of hearing assistance technologies in the workplace, although potentially beneficial to functioning, often serves to identify users as being a member of a stigmatized group (Goffman, 1963). Resources are also available online, to help workers decide whether or not they should disclose their hearing loss to employers and/or co-workers. For example, the Canadian Council on Rehabilitation and Work (2007) posted an online career development portal for Canadians with disabilities. This website provides information on disclosure of disability in the workplace, including, but not limited to considerations relative to job interviews, disclosure (or not) in cover letters, and how to approach requesting accommodations. Less obtrusive accommodations such as job (re)training may help workers perform job duties, and integrate into the social element of work life, but evidence suggests that employees and employers are unaware of available resources (Geyer & Schroedel, 1999; Glass & Elliot, 1993; Jennings & Shaw, 2008; Scherich & Mowry, 1997). Furthermore, employees who do know of workplace accommodations have limited knowledge of how to access them (de Jonge & Rodger, 2006).

## The stigma associated with hearing loss

Individuals are stigmatized when they possess, or are thought to possess, an attribute or characteristic that conveys a social identity that is devalued in a particular social context (Crocker, Major, & Steele, 1998). There are several stereotypes, or commonly held (often erroneous) beliefs about people who have hearing loss. The general public often associate people with hearing loss to undesirable behaviours (Erler & Garstecki, 2002; Jones, Victor, & Vetter, 1984a), ageing (Oyer & Oyer, 1985), and reduced intellect (Doggett, Stein, & Gans, 1998). Stereotypes such as these negatively impact upon activities of daily living engaged in by people with hearing loss, including their workplace activities (Schroedel & Schiff, 1972).

As with other stigmatizing attributes, adults with hearing loss are (virtually always) aware of the relevant stereotypes, and are aware that they may be devalued by others because of their hearing loss (Goffman, 1963). Some people with hearing loss self-stigmatize, that is they agree (consciously or not) with stereotypic views about hearing loss and direct prejudicial attitudes inward (Gagné, Southall, & Jennings, 2009; Major & O'Brien, 2005). Self-stigma serves as a threat to self-efficacy, self-esteem, pride and self-identity (Crocker, et al., 1998; Major & O'Brien, 2005; Steele, Spencer, & Aronson, 2002) and to successful rehabilitation (Gagné, et al., 2009; Southall, Gagné, & Jennings, 2009).

A concealable stigma might be thought of as a stigmatizing characteristic or trait that is not immediately knowable in a social interaction (Quinn, 2006). Workers with concealable stigmatizing traits are regularly confronted by situations whereby they must decide whether or not to reveal this hidden status. Previous work in audiologic rehabilitation suggests that individuals with hearing loss often choose to conceal the existence of hearing loss from co-workers, and that stigma plays an important role in this decision (Hétu, Riverin, Getty, Lalande, & St-Cyr, 1990).

In many instances, the manifestations of hearing loss can be hidden from other people (i.e., co-workers). People who have a concealable stigma (to a large extent) can decide when, how and to whom they reveal information about their stigmatizing attribute. People with hearing loss will often avoid socially demanding situations (Danermark, 1998; Hallberg & Barrenas, 1995; Hallberg & Carlsson, 1991), sometimes conceal manifestations of hearing loss from co-workers (Hétu, 1996; Hétu, et al., 1994) and may be reluctant to acknowledge their hearing loss in the workplace (Hétu, et al., 1990; Lalande, Lambert, & Riverin, 1988). Many individuals who have a concealable stigma attempt to "pass", or keep the stigmatized attribute a secret from others (Goffman, 1963; Jones, Farina, Hastorf, Miller, & Scott, 1984b; Smart & Wegner, 1999; Smart & Wegner, 2000).

The dilemma of whether or not to conceal has been investigated among people with different types of health conditions including epilepsy (Troster, 1997), HIV (Bairan, et al., 2007; Lim, 2003; Wong & Wong, 2006) and mental illnesses (Corrigan & Matthews, 2003; Goldberg, Killeen, & O'Day, 2005; Owen, 2004). An understanding of disclosure among members of lesbian, gay and bisexual (LGB) communities has also been conceptualized using both a *stigma-theory* (Goffman, 1963;(Brackmann, 2003; Ragins & Cornwell, 2001; Ragins, Singh, & Cornwell, 2007) and a *social cognitive theory perspective* (Bandura, 1986, 1997; Croteau, Anderson, & VanderWal, 2008; Lidderdale, Croteau, Anderson, Tovar-Murray, & Davis, 2007).

From a *stigma-theory perspective*, personal and contextual antecedents influence how the individual anticipates and weighs the costs and benefits of disclosure and emphasizes the social costs of disclosure (Croteau, Anderson, & VanderWal, 2008). Ragins (2008) suggested employees who have a concealable stigma are confronted by three challenges. First, employees with a concealable stigma must decide if, to whom, and when to reveal that they have a stigmatizing trait. This decision places an added burden on these individuals (Crocker, et al., 1998; Goffman, 1963; Jones, et al., 1984b). Second, individuals who have concealable stigma are thought to experience anxiety because some people in their work setting likely know that they have a stigmatizing trait, while others are unaware (Goffman, 1963; Jones, et al., 1984b). Managing who knows (and who does not know) about a stigmatizing trait is considered to be an added burden. Finally, individuals who are not completely open about the fact that they have a stigmatizing condition are challenged by a lack of control over who knows and does know about the stigmatizing trait. Ward and Winstanley (2005) conceptualized disclosure in the workplace as not simply a single event, but as a continuing process that is repeated with every new situation and every new person.

There are both benefits and costs of associated with disclosing a stigmatizing trait in the workplace. Disclosure has been described as a means to counteract associations with negative stereotypes, reduce work-related stress, and make one eligible for appropriate accommodations (Creed & Sculley, 2000). Disclosure may also however make one vulnerable to co-workers who hold prejudicial views (Ragins, 2008). Concealing hearing loss can also lead to negative impacts for the individual. For example, concealing a stigmatizing trait prevents the individual from using communication strategies, as doing so would disclose to others that they have hearing loss (Hétu, 1996). Additionally, there are considerable cognitive and emotional resources consumed by attempting to conceal a stigmatizing trait (i.e., hearing loss) and the visible manifestations of this trait (Smart & Wegner, 1999). The stress brought on by concealing or falsifying a stigmatized identity may have harmful effects on psychological and physical health (Crocker & Major, 1989; Major & Gramzow, 1999). This may lead to a decrease in overall quality of life and may be the underlying cause of a number of health related problems (Leary, Tambor, Terdal, & Downs, 1995).

Clair, Beatty, and MacLean (2005) proposed a model that emphasizes individual factors that influence decisions to disclose (or not) and environmental factors that moderate decisions and influence outcomes of disclosure. According to this model, persons are more likely to disclose if they are willing to risk the possibility that they might be the victim of stigmatization, are more skilled at judging whether disclosing might lead to negative consequences, are more self-assured and connected with their difference. The authors propose that these individuals are motivated to maintain their self-esteem and ability to cope in order to preserve or enhance existing social relationships, to access accommodations within the workplace, and to educate others and be a catalyst for change in the workplace. Environmental factors that influence disclosure outcomes include a workplace that supports diversity, through shared values that support disclosing, and organizational policies and procedures designed that ensure and enforce a discrimination-free environment. Furthermore, disclosure outcomes are moderated by transparency in decision-making, whereby employees develop close and trusting relationships with all co-workers including those who have revealed an invisible stigmatizing trait.

From a *social-cognitive perspective*, disclosure is approached by attempting to understand how persons learn about, make sense of, and choose among identity management strategies. From this perspective, the focus is to understand how self-efficacy beliefs and outcome expectations about (a range of) identity management strategies interact with contextual influences to influence cognitions that determine strategy preferences, intentions, and behaviours (Croteau, Anderson, & VanderWal, 2008). Lidderdale and colleagues (2007) proposed a model to understand how behaviour, cognition, and social contexts interact to influence disclosure in the workplace. According to this model, an individual’s level of self-efficacy (beliefs about the ability to perform behaviours) and outcome expectations (beliefs about the outcomes of the behaviours) will determine the choice of behaviours to employ. Individuals with greater exposure to diversity, experiences of diversity being valued, and exposure to persons who openly manage their identity, are likely to have greater self-efficacy beliefs and more positive outcome expectations regarding the employment of an identity management strategy. A person with higher levels of self-efficacy will be more likely to believe that they have the ability to implement a given identity management strategy and to believe that this will lead to positive and valued outcomes. A repertoire of acceptable strategies will be developed as the individual's self-efficacy beliefs and expectations for each new strategy change or are reinforced within the individual's social or work environment (Croteau, Anderson, & VanderWal, 2008).

There is a paucity of empirical literature and limited understanding related to how workers manage information about the existence of their *hearing loss* in workplace settings. We conducted interviews to learn more about the topic of disclosure / concealment of hearing loss in the workplace. In the present paper, we report on factors (e.g., the facilitators and obstacles) that lead individuals to conceal or disclose their hearing loss in the workplace.

## Methods

The present study was approved by the institutional ethics review board of Institut universitaire de gériatrie de Montréal (Montreal, Quebec, Canada), and the University of Western Ontario Health Sciences Research Ethics Board (London, Ontario, Canada). A qualitative descriptive research design (Sandelowski, 2000) was adopted to gain an understanding of the factors that lead to concealing/disclosing hearing loss in the workplace <u>from the perspective of people who have hearing loss</u>. There are two main objectives of qualitative description studies. First, investigators are to observe and learn from respondents in their natural environment (Guba & Lincoln, 1989; Willems, 1967). Second, research findings are to be presented in such a way that is understandable to a lay population, devoid of higher order interpretations such as generated theories (Sandelowski, 2000).

## The respondents

In order to identify common patterns of behaviour that appear across participants, a maximum variation sampling strategy was selected (Patton, 2002). Participants were recruited from three Canadian cities in two provinces (Ottawa and London in Ontario; and Montréal in Québec). The participants in Ottawa were recruited through the National office of the Canadian Hard of Hearing Association; in London participants were recruited through the National Centre for Audiology; and in Montreal through Communicaid for Hearing Impaired Persons (CHIP), a local peer-support organization. Twelve individuals (M=6, F=6) participated in the study (see Appendix 5 at the end of the thesis for more information on the participants). The average age of the participants was 59 years, with an age range from 43 to 73 years (SD = 8.03). All participants reported that their hearing loss was acquired and progressive in nature. No participants reported a pre-lingual onset of hearing loss. Self-reported hearing loss ranged from mild to profound. All participants used hearing aids or cochlear implants, and half of the participants used additional assistive technologies (e.g. amplified telephone). There was also variation in occupation and characteristics of workplace setting. All participants spoke English, worked for wages outside the home at least 20 hours/week, and regularly interacted with at least two other individuals at work. None of the participants exhibited other visible stigmatizing traits (as judged by investigators).

## Data collection

One-to-one interviews were chosen for this study. The interviews were approached with the belief that interviewing is a collaborative process (Holstein & Gubrium, 1995). This empathetic approach to qualitative interviewing (Fontana & Frey, 2005) implies that interviews are a situation bound interaction between two individuals, who each have their own perspective on the conversation.

Prior to the interviews, the participants filled out a workplace questionnaire (see Appendix 3). There were two purposes of this questionnaire. First, the questionnaire was used to collect information about each participant's workplace setting (e.g., size of employer, job duties, environmental challenges) that provided the researchers with a perspective on participant narratives. Second, responses to the questionnaire helped the interviewer pose relevant questions about revealing (concealing) hearing loss in workplace settings. The interviewer made purposeful attempts to create an atmosphere in which the respondent could tell their story. For example, deliberate attempts were made by the interviewer to neutralize any presumptions (on the part of the respondent) of a power dynamic between interviewer and interviewee. To this end, prior to each interview, the first author (who is an experienced interviewer and conducted all of the present interviews) explicitly conveyed to respondents the importance of their contribution in the research process. Statements such as "We are here to learn from you." and "I have normal hearing, I don't know what it is like to have a hearing loss. I am hoping that you can explain it to me." were also introduced into the discussion.

For these audio-recorded interviews, we used an adapted form of photo elicitation. Photo elicitation is a qualitative interviewing technique whereby the interviewer presents a series of images to the interviewee with the intent of provoking a response, evoking memories and extracting information (Clark-Ibanez, 2004; Heisley & Levy, 1991). Collier

(1979) found that photo elicitation improved recall of previous events and in general stimulated communication. Photo-elicitation has been used to examine numerous health related topics and phenomenon, including but not limited to eating disorders (Wessells, 1985); gerontological medicine (Magilvy, Congdon, Nelson, & Craig, 1992) and the maternal stress of mothers who have children with congestive heart failure (Higgins & Highley, 1986). For the present study, ClipArt images (rather than true photographs) of six frequently encountered work situations were selected as stimuli, including job interview, group meeting, speaking on the telephone, lunch with co-workers, social gathering, and one to one conversation. Prior to presenting the first image, the interviewer explained that the images were intended to stimulate conversation on the research topic. Equally importantly, it was explained to the respondents that discussion that extended beyond the six situations to other workplace experiences when the interviewee may have been tempted to conceal or reveal hearing loss was welcome. The interviewer and interviewee gradually worked their way through a PowerPoint slideshow of 18 images (3 x 6 situations) that depicted these workplace activities. For each slide (i.e., image), the interviewer asked three central questions listed in Table 2. When the interviewee referred to personal experiences or perspectives about the stigma associated with acquired hearing loss (stereotypes, prejudice and/or discrimination), the interviewer asked follow-up questions in order to better understand how this issue might have influenced revealing hearing loss in the workplace.

Table 2: Interview guide – article 3

1. How have you handled a situation like this in the past?
2. What motivated you to take that approach to the situation?
3. What were the outcomes (positive, negative, neutral) to this approach?

## Data preparation and analyses

Verbatim transcripts of the interviews were prepared. Within the transcripts, all proper names were assigned pseudonyms and other identifiers were removed to ensure confidentiality. The interview transcripts were analyzed using the content analysis procedure outlined by Elo and Kyngas (2008). Content analysis is a procedure commonly used to analyze textual material (Cole, 1988), and is appropriate for qualitative descriptive studies (Sandelowski, 2000). The primary goal of content analysis is for the investigator(s) to immerse themselves in the data, reading and rereading the transcripts until they are thoroughly familiar with the content (Polit & Beck, 2004). Using content analysis, investigators are able to present a group of concepts that describe a phenomenon (Elo & Kyngas, 2008). This inductive form of content analysis is undertaken without any preconceived theoretical assumptions (Elo & Kyngas, 2008). Content analysis is appropriate when little is known about a phenomenon (Hsieh & Shannon, 2005). Prior to the start of analyses, one key methodological decision was made to analyze both manifest (i.e., spoken) as well as latent content (e.g., gesture). This decision was made to limit the chance of data analysis misunderstandings. Thus, during the interviews, field notes were taken by the interviewer to identify information (such as gestures) not picked up in the audio-recording (Morse & Field, 1995).

Content analysis, as outlined by Elo and Kyngas (2008) has three steps: open coding, creating categories, and abstraction. The goal of open coding is to search for text that answers the fundamental research questions. Transcripts are read line by line. Upon identification of relevant text, a "heading" is assigned in the margin of the transcript. In open coding, investigators are encouraged to assign as many headings as are required to fully describe the content of the text (Hsieh & Shannon, 2005). Next, the headings listed in the margins are reviewed and categories of headings created (Burnard, 1991). This is essentially a preparatory step performed to make reporting easier (Cavanagh, 1997). The final step of content analysis is abstraction, when investigators prepare general descriptors of the data (Polit & Beck, 2004). In the present study abstraction involved uploading the data into ATLAS-ti (2004), a software program designed to aid in the analysis of large bodies of text. ATLAS-ti provides an interface whereby researchers can quickly move about text-based documents in order to examine how the interviews and assigned categories relate with one another. During this phase of content analysis, meaningful patterns within and across interview transcripts (such as the frequency with which categories appear in proximity to one another in the text) were identified (Morse & Field, 1995). In this phase of analysis, ATLAS-ti was used primarily as a data management tool. Accordingly, it was up to the investigators to decide what interview passages were relevant, and how to categorize selected excerpts. Data analyses continued until it became evident that extending analyses would produce no new information (Morse & Field, 1995).

Two strategies were employed to increase the trustworthiness of the findings (Fetterman, 1989). First, attempts were made to provide a detailed and thorough characterization of the factors that influence disclosure of hearing loss in the workplace. Thus, in this text, ample space was devoted for interview excerpts and investigator interpretations. Second, the study findings were evaluated for trustworthiness using "*member checking*". One respondent, and two individuals who have hearing loss and are knowledgeable of the psychosocial implications of hearing loss (both serve for peer support group organizations for individuals with hearing loss) reviewed the findings of this study. These three individuals confirmed that the themes reported in this manuscript are reasonable and encountered by workers with hearing loss.

## Findings

Analyses of the interviews revealed five overarching themes that influenced revealing or concealing hearing loss in the workplace: perceived importance of the situation, perceived sense of control, community affiliation, burden of communication, and coexisting issues related to hearing loss (see Table 3). The interview excerpts included in this section were judged to be representative of patterns across interviews.

Table 3: Themes and Sub-themes arising from the content analysis

| Theme | Sub-theme 1 | Sub-theme 2 |
|---|---|---|
| Perceived Importance of the Situation | perceived responsibility in the situation | costs versus benefits of revealing hearing loss in the given situation |
| Perceived 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 |
| Burden of Communication | perception that co-workers forget about their 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 | maintenance and visibility of adaptive technologies |

## Theme 1: Perceived importance of the situation

The respondents explained that some situations in the workplace warranted revealing hearing difficulties, while other situations did not. Some workplace situations were described to be innocuous, and revealing hearing loss would have been considered unnecessary or a behaviour out of the ordinary. Whereas, other workplace situations were perceived by participants to be important, and the decision to reveal (or conceal) hearing loss was crucial. This differentiation among levels of importance is an analytical approach to managing who knows, and who does not know about one's hearing loss whereby a decision or choice is made. The theme *Perceived Importance of the Situation* included two sub-themes related to disclosing hearing loss in the workplace: a) *perceived responsibility in the situation*; and b) *costs versus benefits of revealing hearing loss in the given situation*.

### Perceived responsibility in the situation

Mike, an Engineer, explained that it was personally important for him to effectively manage workplace duties, and to be perceived by colleagues as a good worker. His work often involved organizing teleconferences. Communication difficulties during these calls were particularly stressful for him because *he* convened the meeting, and *he* was ultimately responsible to ensure that the group successfully accomplished their objectives. Mike explained that during these calls he was often forced to reveal his own communication problems, because he felt a responsibility to perform his work duties well.

*"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."*

### Costs versus benefits of revealing hearing loss in the given situation

Prior to entering into a challenging workplace environment, some respondents anticipated communication difficulties, and thus weighed the costs against the benefits of revealing their hearing loss. In one interview, Lisa, who worked in a government office, rationalized her decision to conceal her hearing loss during a recent job interview. She explained that the benefits of being offered this new / better job far outweighed the complications that would likely arise later, when her new employer learned of her communication problems.

*"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."*

Zola, a social worker, used a slightly different approach. When weighing the costs and benefits of revealing her hearing loss Zola tried to consider the situation from her boss's perspective.

*"I am low man on the totem pole. I mean there are children being abused, and newspapers calling to find out why did this child die in a foster home. [My boss] gets bombarded with things. So [my hearing difficulties are] not high on their list, [so] I let it go."*

## Theme 2. Perceived sense of control

The respondents explained that revealing their hearing loss was often influenced by confidence in their own ability to manage future events (i.e., to "successfully" reveal or conceal hearing loss in the workplace). Sometimes there were specific aspects of the social or physical environment that provided the respondents with a sense of confidence that they could manage the *situation*. Other times confidence came from within, and respondents believed that they could "successfully" manage the *foreseen consequences* of revealing their hearing loss. *Perceived Sense of Control* was influenced most by: a) *the predictability of work related tasks*; and b) the *balance of power between the worker with hearing loss and the co-worker*.

## Predictability of work related tasks

The predictability of work related tasks influenced the respondent's sense of control in a given situation, and influenced their inclination to reveal (or not) their hearing loss. For example, in separate interviews, both Janice (a Hotel Sales Manager) and Gary (an Engineering Consultant) described their experiences making sales calls. Both rationalized their choice to conceal their hearing loss, because the predictability of sales calls gave them a sense of control. For these two respondents, who each had years of experience making sales calls, this was a predictable task. Each explained efforts made to control this situation, thereby eliminating the need to reveal their hearing loss. First, Janice described how she '*did her homework'* before making the phone call in order to avoid communication breakdowns and thus reduce the chances that she will have to reveal her hearing loss.

*"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…I already know that (they currently stay with) the Sheraton, so I don't have to ask them."*

For Gary, the key objective of a sales call was to convince the prospective client to meet face to face. In his experience, all non-relevant information should be excluded from the phone call, because it increases the possibility of communication difficulties, and jeopardizes that the potential client will not make an offer to meet face to face.

*"You have to sell them on the on the fact that they want to see you again. [Interviewer: Do you say, "I have a hearing loss?"] No. Don't interrupt the conversation with things that don't matter. In that situation, I guess it comes back to commanding the situation."*

### Balance of power between the worker with hearing loss and the co-worker

The inclination to reveal one's hearing difficulties sometimes hinged on the balance of power that existed between the worker with hearing loss and other co-workers present in a given situation. In two of his jobs, Gary worked in large noisy plants where he was in charge of equipment that often required maintenance. Employees would frequently come to Gary and describe problems that they were having with a piece of equipment. In many instances, employees would lead Gary to the plant floor to show him the problem. The noisy environment and Gary's tendency to conceal his hearing loss complicated these situations. The following is an example of how Gary used his expertise and position of power to overcome a noisy environment and the need to reveal his hearing difficulties at work.

*"I knew enough about (my job) that I could wing it. And I mean, if somebody takes me to see a problem, points out a problem, and then 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, and you know you'd pushed the right button…. (or) "We're going to have to look at that…" (laughs). Which means I will need to get out of here and do some thinking about it. "*

## Theme 3. Community affiliation

The respondents in this study described how social cohesion that exists in the workplace had an influence over inclination to reveal hearing loss. Each respondent in their own manner explained that they had a desire to feel part of the workplace team. But for many respondents, hearing difficulties served as a barrier to social inclusion. Perceived social inclusion impacted upon proclivity to reveal hearing loss. We referred to this idea as community affiliation. Like the other themes, *Community Affiliation* is divided into two sub themes: a) *community affiliation jeopardized because hearing loss not considered 'normal'*; and b) *difficult to understand "partial" hearing loss.*

### Community affiliation jeopardized because hearing loss not considered 'normal'

The idea of "normal" came up repeatedly in the interviews. Lisa, a government employee, indicated that she was at ease with her hearing loss and was comfortable revealing her hearing loss at work, but her community affiliation was challenged by co-workers who had prejudicial attitudes about hearing loss.

*"I've got a hearing deficiency. I don't have a brain deficiency. So quit treating me like an idiot. Some people are really in the stone ages."*

Other respondents stated that they were apprehensive about requesting special accommodations (e.g., communication strategies) from co-workers, as these requests were not *normal.* According to these respondents, requests for accommodations signaled to co-workers that something was wrong (i.e., abnormal). Julie, a buyer spoke to this point.

*"You don't like to do that all the time. 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."*

## Difficult to understand "partial" hearing loss

Brian, a gentleman who worked as an airport shuttle bus driver, provided the most striking description of social exclusion. Brian described why he thinks stereotypes about hearing loss still exist. He felt that the general population does not understand the concept of partial hearing loss. Brian explained that both normal hearing and clinical deafness are apparent, whereas partial hearing loss is not.

*Because you can hear partially, I think it's as big a frustration as not being able to hear, cause* [society] *can't handle that. They don't know how to treat you. They don't know... "Oh yeah, you can hear. That's ok". If you're completely deaf, they have a different attitude* [about] *you, cause it's apparent. When you have a partial hearing loss, it's not so apparent. And it's kinda like a no-man's-land sort of thing. What do you do? How do you work with somebody [like that]?"*

Brian went on to explain what it feels like to live in "no-man's-land", and how the general public's lack of understanding has impacted him.

"[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. I know it sounds kind of silly, but... it's a peculiar sensation...I don't know how to describe it, but it exists."*

## Theme 4. Burden of communication

The respondents explained that communication with co-workers was made more difficult due to manifestations of hearing loss. According to the respondents, some co-workers responded favourably to communication challenges and other manifestations of hearing loss (e.g., by accepting to repeat), while other co-workers responded less favourably (e.g., breaking off conversation). The respondents indicated that they would sometimes anticipate how co-workers would react or respond to communication challenges. These anticipatory processes influenced subsequent decisions of revealing or not hearing loss. The theme, *Burden of Communication* was divided into two sub themes: a) *perception that co-workers forget about their hearing loss*; and b) *perception that hearing loss is disruptive to natural flow of interactions.*

### Perception that co-workers forget about their hearing loss

For respondents who had already revealed their hearing loss to co-workers, there was the general perception that co-workers forgot about their hearing loss, and forgot about the communication difficulties that the worker manages everyday.

Some respondents became upset when co-workers forgot to account for their hearing loss. Periodically, respondents confronted co-workers, about forgetting to adapt their behaviours to account for the hearing loss. The respondents viewed this confrontation as an unnecessary *re-revealing* of hearing loss. For example, Eric regularly had to remind one co-worker about his hearing loss, until he became so frustrated by this that he started to cut off all communication with this co-worker. *"He forgets, and I usually have to do this* [not to speak with the co-worker for the remainder of the workday] *about every time he's with me. At some point enough is enough."* Larry, who did not conceal his hearing loss from co-workers indicated that there were times when he was frustrated by co-workers, *"they called a big meeting, and they have absolutely no accommodation for me. I walked out. I was pissed. The manager* [said] *"oh I'm sorry". How could you forget? How could you possibly forget?"* Other respondents claimed that it is not so much forgetting about hearing loss, but the co-workers simply do not know how to communicate with people who have hearing loss. Janice said, *"People forget. They don't know how to deal with a hearing impaired person..."* Other respondents understood that co-workers might forget their hearing loss. For example Zola, the social worker, whose hair covers her hearing aids said, "*people forget that I am hearing impaired, because they don't see anything, they don't see my hearing aids".* Mike, the engineer did not disparage co-workers if they forgot, reasoning that, "*It's not something that they intuitively know."*

**Perception that hearing loss is disruptive to natural flow of interactions**

Mike explained that his hearing loss often disrupted the *natural* flow of the conversation at meetings. He explained that he would frequently assess the flow of communication and if he judged that his hearing loss was obviously having a negative impact, he may be inclined to reveal his hearing difficulties, or ask for help.

*"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. Otherwise if I think it's within the realms of the average person that asks something to be repeated then I won't, I won't say anything."*

Mike went on to explain that the decision to reveal (or not) his hearing loss may depend on the other workers present and the rapport that he had with these individuals. With a select group of co-workers he felt comfortable if there lacked a smooth flow of conversation (i.e., other than natural).

*"I have a group of four guys that I usually lunch with, and they know that it's hard for me to hear sometimes, so it's not a problem to ask them to repeat something four or five times, but if I'm going out on a larger group I'm reluctant to do it."*

## Theme 5. Coexisting issues related to hearing loss

As a group, the respondents identified a host of other factors specific to their personal situation that influenced revealing their hearing loss in the workplace. The theme *Coexisting Issues Related to Hearing Loss* is divided into two sub-themes: a) *issues that result in fluctuating levels of hearing ability*; and b) *maintenance and visibility of adaptive technologies.*

### Issues that result in fluctuating levels of hearing ability

Several respondents stated that their fluctuations in hearing ability posed an additional burden (or at the least, consideration) when deciding whether or not to reveal their hearing loss at work. For example, some respondents expressed that co-workers did not understand the manifestations of tinnitus. Diane, a family physician/researcher, speculated that daily fluctuations in her tinnitus likely made it difficult for her co-workers to know how to interact with her. She indicated that if she wanted to be completely open with co-workers, she would have to reveal her audiologic situation (i.e., hearing loss and tinnitus) everyday. In the following excerpt, Diane discussed this personal aspect of revealing, and how providing regular updates to co-workers was challenging to her and to them.

*"It's very hard for me to help people understand that, and it's very hard for them, when one day I'm just fine and the next day it's difficult to hear what they are saying. I just wish I had*

*a thermometer on my head that showed people what it was like today. It makes me feel that I am...I feel embarrassed that I have this fluctuation in levels. People never know where I am at. Some people are accommodating with that, and others just don't cope as well…Hearing loss is a hidden disability and to have tinnitus is sort of like a double whammy. It's not constant. I find it's hard, but it's not a constant issue."*

### Adaptive technologies and other accommodations

As with many of the other topics previously discussed, adaptive technologies and other accommodations served as both a facilitator and as a barrier to respondents revealing their hearing loss in the workplace. First, many respondents explained that the visibility of hearing aids (and other technologies) took away some of the control that workers had regarding when and to whom they revealed hearing loss.

*"When I was about to get hearing aids, it was a tough thing for me to accept, because of the visibility… I didn't want people know I was hard of hearing"*

Other respondents however had a different perspective about the visibility of technologies. These respondents explained that the visibility of hearing aids did the revealing for them.

*"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."*

Finally, a few respondents described the importance of being prepared to disclose. These individuals explained that revealing hearing loss in the workplace can be empowering both at the individual level (e.g., opportunity to work in more favourable environment) as well as at the societal level (e.g., opportunity to combat stereotypes).

*"If you sell yourself and say, "I can do absolutely everything here, but I can't hear on the phone. But this is how we're going to deal with it, this is where you can get the devices, this is how much it costs, this is what's done out there by other agencies…" That's empowering. It's not simply the disclosure, you have to be prepared to disclose*."

## Discussion

Hearing health care professionals may not recognize that telling others about the presence of a hearing loss and asking for accommodations to improve communication in the workplace can have important implications for persons with hearing loss. The connection between telling others, requesting accommodations and "disclosure" is often not made. People who have hearing loss are often at liberty to decide if, when, and under what circumstances to disclose their hearing loss to work colleagues. Analyses revealed that respondents seemed to attend to issues of disclosure, with thoughts extending both prior to a potentially stigmatizing event, as well as afterward. Participants in this study approached disclosure of hearing loss in the workplace in a somewhat systematic and reasoned manner. For most respondents, the principal decision was to evaluate if they could function in the situation without revealing. If the answer was yes, they strategized how to achieve this goal. If the answer is no, they weighed the costs and benefits of disclosing. If the benefits outweighed the costs, they strategized how to disclose while preserving self-integrity.

Disclosure, for these respondents, was revisited every time a co-worker forgot about the hearing loss, when new situations arose and when new people entered the scene. This experience is consistent with Ward and Winstanley's (2005, p. 453) description of disclosure as a "repetitive iterative process." Analyses revealed that respondents routinely thought about disclosure of hearing loss, and strategized how to control information flow about their hearing loss in various workplace scenarios. Consistent with a *social cognitive perspective* of disclosure, respondents considered their level of confidence in the ability to manage future events and to successfully disclose or reveal (Croteau, Anderson, & VanderWal, 2008; Lidderdale, et al., 2007). We understood this to be an on-the-spot evaluation of the anticipated benefits versus the anticipated negative consequences of disclosure of hearing loss. Some respondents mentioned that they anticipated benefits resulting from disclosure of hearing loss to coworkers. Examples of anticipated disclosure benefits included: opportunities to educate co-workers about the nature of hearing loss, providing kinship to co-workers who also had hearing loss, the expectation that disclosure would provide a boost to their self-esteem by putting a disparaging co-worker in their place. Respondents also mentioned many negative or potentially negative anticipated consequences of disclosure. For example, disclosure to a superior could result in an unsuccessful job hire, being denied a promotion or being fired. It could also result in social isolation, harassment, verbal abuse or being made fun of. We deduced that participants would engage in this cost-benefit analysis, hoping to formulate a reasonable manner to conceal their hearing loss. These processes are generally consistent with behaviour change conceptual frameworks (e.g., Theory of Reasoned Action: Fishbein & Ajzen, 1975). The anticipated benefits and negative consequences of disclosure in the workplace described by respondents are consistent with those reported by persons with other invisible stigmatizing traits (Ellison, Rissinova, MacDonald-Wilson, & Lyass, 2003; King, Reilly, & Hebl, 2008; Madaus, 2008; Ward & Winstanley, 2005) and with *stigma-theory perspectives* of disclosure (Clair, et al., 2005; Ragins & Cornwell, 2001).

Hearing loss tends to reveal itself. Recurrent communication breakdowns are in fact one form of disclosure. Thus, a worker who repeatedly conceals hearing loss from co-workers risks experiencing communication problems and being "outed". If a worker with hearing loss is in the habit of concealing (as were these respondents), they may be conscious of (and attentive to) communication difficulties, as these may give rise to suspicions among co-workers, and could well jeopardize keeping the hearing loss concealed. Stress is another important burden associated with hearing loss stigma. This issue has been discussed extensively elsewhere (Gagné, et al., 2009).

Conceptually, these findings may also be viewed from the perspective of the individuals who stigmatize. Recent work suggests that prejudice is rarely based solely on a simple negative evaluation of another person. Cambon and colleagues (2006) reported that there now exists considerable evidence that social judgments made about other people are made along two dimensions; Dubois and Beauvois (2005) termed these dimensions *social utility and social desirability*. *Social utility* reflects an individual's capacity to successfully carry out the duties expected by an organization or social group, typically involving characteristics such as competence, independence and confidence. *Social desirability* is reflected in an individual's capacity to be perceived by others as likeable, this includes attributes like sincerity, friendliness and compassion. Evidence suggests that outsiders rarely hold negative opinions of other people along both dimensions (Fiske, Cuddy, Glick, & Xu, 2002). Rather, outsiders almost always hold a positive view for one dimension and a negative for the other dimension. These findings present a very interesting twist for the present study. A co-worker may likely have ambivalent evaluations of a worker with hearing loss, whereby the co-worker evaluates the colleague with hearing loss positively in one dimension and negatively in the other dimension. A co-worker who has prejudicial attitudes about people with disabilities for the social utility dimension could very well be friendly in the lunchroom, but critical and disparaging in a meeting. This obviously makes it very difficult for a person with hearing loss to predict how co-workers are going to behave from one situation to the next. Yet, it seems that in assessing whether or not to disclose (or not) their impairment, workers with hearing loss continually make judgments (perhaps not always completely valid) about how there are perceived by their co-workers.

Social psychology or sociological models of behaviour are often used to conceptualize stigma and social deviance (Blumer, 1969; Link, Cullen, Struening, Shrout, & et al., 1989; Markowitz, 2005; Mead, 1934). These conceptualizations provide a general discussion of sociological constructs, and how these impact upon the generation and response to stigmatization. The themes arising from analyses (in particular: Perceived Sense of Control, Community Affiliation and Coexisting Issues Related to Hearing Loss) are suitable to be considered using a sociological perspective on stigma.

The inclination to disclose a stigmatizing trait in the workplace is likely influenced by social and environmental characteristics and the culture of the workplace. The presence of other workers who have the same or similar stigmatizing attributes who openly manage their identity may aid workers with hearing loss to make the disclosure decision (Ragins, 2008). Support may come in the form of friendliness and supportive alliances with other co-workers (Ensari & Miller, 2006; Ragins, et al., 2007). These individuals may be able to help, guide or support the worker through the process of gradually disclosing to other people in the workplace.

People with hearing loss may also derive organizational support based on the size of employer, the occupation, and nature of work. As previously mentioned, the Canadian province of Ontario passed the Accessibility for Ontarians with Disabilities Act, 2005. While the goal of this legislation is to make the province accessible to all people with disabilities by 2025, the extent to which the proposed guidelines are put into practice in private and public Ontario firms contributes to propensity to disclose. Factors such as practices and policies concerning employees who have disabilities, whether the employer is a private enterprise or public entity, proportion of employees that have disabling conditions, practices concerning provision of technical and other accommodations for workers with disabilities, and even existence of an employee handbook all factor into the perceived environmental support felt by workers with concealable stigmatizing traits and likely impact upon disclosure.

## Clinical implications

The findings of this study highlight the need for rehabilitation programs that address identity management strategies, and more specifically the concealing and disclosing of hearing loss in the workplace. While we did not solicit information about previous rehabilitation services, some of the respondents in this study were recruited through consumer groups for persons with hearing loss. The respondents revealed that they analyzed threatening workplace situations, assessing and predicting how specific coworkers would respond to disclosure, and assessing how their own strengths and weaknesses might impact upon disclosure. We hypothesize that the respondents developed these skills by retaining information about previous disclosure episodes, and using these practical experiences in order to manage future workplace disclosure situations more easily.

The first step in any rehabilitation program is to have the worker with hearing loss participate in a thorough program of assessment. Kramer (2008) described a Vocational Enablement Protocol that includes a comprehensive assessment of workplace difficulties, diagnostic hearing testing, assessment of coping abilities, on-site workplace assessment (if indicated), and recommendations to facilitate the workers continued participation in the workplace.

Partnerships between hearing health care professionals and occupational therapists (or others who have specific training in workplace issues and disclosure) would be beneficial in developing and implementing pertinent programs for workers with hearing loss (Hétu & Getty, 1991; Jennings & Shaw, 2008; Kramer, 2008). Persons with hearing loss who have experience with disclosure in the workplace can act as partners and mentors within these programs. Participants would be encouraged to invite a significant other, and/or a close co-worker to attend the program to increase their understanding of the implications of hearing loss in both the workplace and outside the workplace and to support them in dealing effectively with any experiences of third-party disability (Hickson & Scarinci, 2007).

Prior to, and ongoing with these programs, participants should be supported in using a goal setting process (such as Goal Attainment Scaling) that is used to organize the rehabilitation process through involving the participant and any key significant others in setting personal goals that are specific to workplace identity management (Jennings, Gagné, & Southall, 2009). The use of Goal Attainment Scaling (Kiresuk & Sherman, 1968; Kiresuk, Smith, & Cardillo, 1994) involves the collaborative setting of rehabilitation goals using small steps to reach each goal and clearly stating who will do what, under what conditions, and to what degree of success. Goal Attainment Scaling provides a means for qualitative and quantitative documentation of outcomes of change on specific goals over time. Components of the rehabilitation program can be chosen to support the participant in meeting their personal goals for change.

Intervention programs informed by both stigma-theory and social cognitive theory perspectives would be appropriate. The objective of such programs would be to support workers with hearing loss to increase their self-efficacy for managing their identity in the workplace and to increase their repertoire of identity-management strategies. As with other audiologic rehabilitation programs, these programs would include pertinent information components on communication and environment management strategies, hearing assistive technologies appropriate to the workplace, assertiveness training, how to disclose hearing loss, and stress management, i.e., the manifestations and consequences of stress and practical suggestions on how to reduce tension and anxiety (Gagné & Jennings, 2008; Getty & Hétu, 1991; Jennings, 2005; Trychin, 2003a; Trychin, 2003b; Trychin, 2003c, 2003d). It is also important to include information related to privacy issues related to disclosure and current legislation in place to support equality in the workplace. Participants with hearing loss can be provided with information about organizations and online resources specifically related to workers with hearing loss. Some of these include UK Health Professionals with Hearing Loss (www.hphl.org.uk), Association of Medical Professionals with Hearing Loss (www.amphl.org), Exceptional Nurse (www.exceptionalnurse.com), and Nursetogether.com ™ Empowering Nurses Globally (www.nursetogether.com).

Specific to building self-efficacy, activities within the program would target change within *processes that regulate human functioning*; cognitions, motivation, affective responses, and the types of activities and environments in which the person chooses to participate (Bandura, 1997). Activities would include the sources of self-efficacy information identified by Bandura (1997), mastery experiences (that provide the participant with information that they can succeed – for e.g. role play), vicarious experiences (that provide the person with evidence that if others can do it, so can they – for e.g. modeling), social persuasion experiences (that provide the individual with support and persuasion from valued and respected others – for e.g. through discussion, feedback and encouragement), and through targeting somatic and emotional responses (providing training in interpretation of stress reactions and tension as a facilitator rather than a inhibitor of action). Programs could be informed by a stigma-theory approach through providing training in the use of a problem-solving approach that includes a cost-benefit analysis of the choice and application of specific identity management strategies (Gagné & Jennings, 2008).

# Conclusion

The purpose of this study was to identify the factors that lead individuals to conceal or disclose their hearing loss in the workplace. We conducted semi-structured interviews using a photo-elicitation technique to aid in probing issues related to disclosure of hearing loss. Emergent themes included: Perceived importance of the situation, Perceived sense of control, Community affiliation, Burden of Communication and Coexisting issues related to hearing loss. The findings of this study provide a glimpse into the hidden world of workers with hearing loss. This study serves to document some of the ways that workers with hearing loss manage their workplace identity, and more specifically, how some people with hearing loss deal with the dilemma of to disclose or not to disclose. The findings also inform the development of pertinent intervention programs for workers with hearing loss.

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# Chapter Five: Discussion

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The findings and interpretations arising from this study are generally consistent with the stigma-induced identity threat model of Major and O'Brien (2005). The results of the *help-seeking* study demonstrated that stigmatizing attitudes and discrimination found in the respondent's social and work life impacted upon help-seeking activities. The respondents explained that their (voluntary) efforts to seek help followed "critical junctures", when the negative stress far outweighed positive energy, as well as when positive energy far outweighed the negative stress. We proposed a series of graphic representations that depict the balance of positive and negative resources found in the respondent's social and physical environment.

Furthermore, the three phases drawn from analyses are consistent with the basic tenets of the Major and O'Brien model. The respondents described the early years following the identification of hearing loss to be quite stressful. Although the respondents characterized this to be a time of mounting stress, analyses revealed that relative to other phases, there was an equilibrium between demands and resources (the top representation from Figure 1: p.22). Help seeking efforts became more important following particularly intense phases of the respondent's life, when challenges of hearing loss as well as other stressful life events exceeded personal resources. When confronted by Critical Juncture One, respondents attempted to seek help in order to problem-solve (Miller & Kaiser, 2001). In the third phase, the respondents described a time on their lives when there was an abundance of positive influences. During this time, respondents indicated that they were open to seek help or to learn more about rehabilitative opportunities. Analyses suggest that in this phase the respondent's personal resources (box C) far exceeded the demands posed by stigma related identity threats. They were thus in a position where they had extra resources available to consider learning more about rehabilitative alternatives. The respondents also indicated that this was a time when they decided to become involved with peer-support groups. Peer-group involvement is often accompanied by benefits including educational and instrumental support, social validation and a sense of belonging (Major and O'Brien, 2005). These findings generally support the *resources* concept (initially proposed by Lazarus and Folkman, 1984) that became the centrepiece of the stigma-induced identity threat model of Major and O'Brien (2005). The series of graphic representations proposed in the discussion of Chapter Three raise interesting questions about how positive influences can alter the experience of stigmatization.

It should be noted that there was also an unmistakable resemblance between the *evolution* of identity threats experienced by the respondents in the help-seeking study, and the landmarks of identity integration model proposed by Cass (1979) described in the literature review chapter of this thesis. In Article 2, we found that the respondents described three important phases associated to hearing loss stigma and help-seeking: a gradual build-up of stress; critical juncture one, characterized by social and workplace losses leading to unmanageable stress; and critical juncture two, in which we found new positive influences in life enabled positive attitudes toward hearing loss and help-seeking. These findings generally align well to Cass' identity integration model. Cass (1979) proposed a series of landmarks inherent to integrating a gay-lesbian-transgender identity into the self-concept: *identity confusion, identity comparison, identity tolerance, identity acceptance, identity pride and identity synthesis.*

Chapter Four was a manuscript entitled "Factors that influence disclosure of hearing loss in the workplace". The purpose of the study was to identify the factors that lead individuals to conceal or disclose their hearing loss in the workplace. We chose this topic because research that focussed on other stigmatizing traits (e.g., mental illness), has demonstrated that there are important psychological costs associated with concealing a stigmatizing trait (Ahern, Stuber, & Galea, 2007; Pachankis, 2007; Vanable, Carey, Blair,

& Littlewood, 2006). To our knowledge, no study has investigated disclosure of hearing loss in the workplace. Based on the stigma-induced identity threat model, disclosure of hearing loss is a volitional response (i.e., box F). Thus, the decision to conceal or reveal hearing difficulties is influenced by all of the antecedents to identity threats (boxes A, B and C), by discrete and unique identity threats (box D), perhaps by non-volitional responses (box E) and by outcomes to previous coping responses (box G).

Analyses uncovered five recurring themes that prompted respondents to conceal or disclose their hearing loss in the workplace. These themes included: Perceived importance of the situation, Perceived sense of control, Community affiliation, Burden of Communication and Coexisting issues related to hearing loss. The respondents in this study explained that their default stance was to conceal their hearing loss in workplace settings. Only when circumstances absolutely warranted disclosure did respondents indicate to co-workers that they had a hearing loss. This (voluntary) response to challenging workplace situations is consistent with previous research conducted within audiologic rehabilitation. For example, avoidance and withdrawal (be it physical or psychological) are passive volitional (or perhaps nonvolitional) responses to stressful situations. Numerous authors have reported use of avoidance strategies by persons with stigmatizing traits (Hallberg & Carlsson, 1993; Hallberg & Barrenas, 1995; Major & Schmader, 1998; Steele, 1997).

The motivations to conceal hearing loss found in the workplace study are easily incorporated into the stigma-induced identity threat model (Major and O'Brien, 2005). The respondents described personal characteristics, i.e., box C that led them to conceal their hearing loss, such as fluctuating levels of hearing ability, i.e., subtheme 5, the balance of power that existed between the worker and coworkers, i.e., subtheme 2, and the personal benefits and costs of revealing, i.e., subtheme 1. The respondents also documented many situational cues, i.e., box B that led to concealing or revealing hearing loss in the workplace. For example, some respondents reflected on the predictability of work-related tasks, i.e., subtheme 2, the extent to which coworkers would understand partial hearing loss, i.e., subtheme 3, and the availability of workplace accommodations, i.e., subtheme 5. Finally, the respondents described some collective representations, i.e., box A that prompted concealing hearing loss at work. Examples of collective representations arising from analyses include the extent to which hearing loss disrupts the natural flow of conversation, i.e., subtheme 4, and that hearing loss is not considered “normal”, i.e., subtheme 3. Thus, in general, the themes arising from the workplace study appear to support the Major and O’Brien framework.

It is noteworthy that respondents repeatedly described how they would *anticipate* and plan their responses to workplace identity threats. For example, respondents explained how they contemplated disclosure scenarios for job interviews. This may be a reflection of the photo elicitation technique used for this study, a technique that required respondents to consider various workplace scenarios. Anticipating episodes of disclosure may also simply be an outcome of concealing a stigmatizing trait. Previous authors have reported that concealing a stigmatizing trait can pre-occupy thoughts, and use up personal resources that could be used for more constructive activities (Smart & Wegner, 1999). However, one could also reasonably contend that for a person who has hearing loss, the workplace potentially represents a highly threatening setting. Workplace discrimination could well result in termination of employment. Stigma-induced workplace threats therefore potentially have tangible consequences for the worker with hearing loss and his or her family. From this perspective, it is reasonable for participants to have considered and planned disclosure in a detailed manner.

As mentioned in the literature review chapter of this dissertation, it is important to note that there are other informative stigma process models that are useful to understanding stigmatizing attributes. The Labelling theory (Link & Phelan, 2001), for example, is particularly interesting in this regard. In both studies, we found that for some respondents it was difficult to continue on with their present work due to manifestations of their hearing loss. Some respondents made illusions to possessing a Protestant work ethic. These respondents were brought up (i.e., socialized) to value a full and hard day's work. After the onset of their hearing loss, some respondents indicated that it was hard for them to reconcile their own feelings about hearing loss, because they were no longer able to live up to their own expectations. These respondents applied stereotypes to themselves (i.e., self-stigmatized). Although a full exploration of these alternate models goes beyond the scope of this dissertation, the preceding lines give an idea of how sociological models could be applied to this subject.

## Practical/clinical implications

As discussed in the three manuscripts, the stigma-induced identity threat model is potentially a useful resource for hearing health practitioners. The model maps out the components of the stigma process, the antecedents to identity threats as well as categorized responses that may result from identity threats. The model itself may thus constitute a valuable resource for clinicians who work with adults who have acquired hearing loss.

The Major and O'Brien (2005) conceptual model also provides insights into the rehabilitative techniques suitable for people with hearing loss who perceive themselves to be stigmatized. A fundamental premise of the stigma-induced identity threat model is that the coping responses used to deal with any stressful event are not different from expected responses to the stress induced by an identity threat. Thus, the theoretical foundation of the Major and O'Brien model (ie., stress and coping: Lazarus and Folkman) serves to validate existing audiologic programming designed to *reduce the stress* associated with specific aspects of having a hearing loss (Jennings, 1993; Trychin, 1986; Wayner & Abrahamson, 1996).

People with hearing loss, their family and friends and hearing health care providers may all benefit by learning more about hearing loss stigma, and how stigma impacts daily activities such as those examined within this dissertation. All of these individuals would benefit by a greater understanding of stigma, using the stigma-induced identity threat model (Major & O'Brien, 2005). The heart of the model is found in the stress that is induced by identity threats. Individuals with hearing loss who may not be conscious of (or who deny) that they are susceptible to stigmatization would likely benefit by being able to identify the sources of stress that they experience in some situations. This information may also provide the impetus to reflect upon the types of coping strategies (and the effectiveness of the strategies) used in those situations.

In clinical settings individuals with hearing loss, their family / friends and clinicians may work together, and strategize how to manage and reduce the stress associated with identity threats and stigmatization. The dissemination and greater understanding of the stereotypes associated with hearing loss. For people with hearing loss this may serve to diminish their stress, as they may recognize that many stereotypes about hearing loss are ill-founded or simply untrue. Moreover, adults with acquired hearing loss are likely to be comforted and calmed to learn that many many people are in the same situation, they are actually members of a very large group of insiders (i.e., adults with acquired hearing loss). For family and friends, a basic understanding of the stigma process may provide some explanations of misunderstood attitudes and behaviours coming from their loved ones.

Clinicians might be well advised to speak with their clients and assess their client’s readiness for help-seeking. That is to say if there is an accumulation of positive or negative influences present, their client may be prepared for a new rehabilitative solution. Moreover, the studies presented in Chapters Three and Four both revealed benefits of peer-support. Clinicians should undertake all reasonable efforts to identify, collect and disseminate information about the peer-support groups working locally and refer clients early and often to activities offered by these groups. There seem to be indications that these groups benefit individuals with hearing loss insofar as group members learn from one another, and the group can serve as a buttress against societal threats.

## Avenues for future research

Based on the theoretical paper and the findings from the two studies, as a first approximation, the Major and O’Brien model (2005) appears to provide a coherent framework with which to consider situations that are stigmatizing to people with hearing loss. This has a variety of implications for people who work with this population. Below, is a discussion of some of the theoretical and practical/clinical implications of this dissertation.

From a theoretical perspective, the stigma-induced identity threat model serves to integrate (disconnected) information about the stigma associated with hearing loss. In this regard the model is quite useful, as stigmatization is a complex and multi-faceted phenomenon that can be difficult to fully grasp. Identity threats (i.e., Box D), and the theoretical foundation on which it is based, serve to integrate information about the antecedents to identity threats (i.e., the personal factors, situational factors and collective representations) with information about coping responses and outcomes. By integrating information about hearing loss stigma into a practical configuration, this model makes this phenomenon more accessible.

The Major and O'Brien stigma-induced identity threat model (2005) also serves to identify new promising research questions. Using this model it is relatively uncomplicated to understand how the application of a stereotype can lead to threats to one's identity. However, what is less obvious is the appropriateness of the model for people who possess more than one stigmatizing attribute. There are stigmas associated with many chronic health conditions that emerge late in life. The experiences of one participant from the peer-support study were interesting in this regard. This gentleman had both a hearing loss and a vision loss, but approached help seeking for these two conditions in very different ways. This individual was quite comfortable seeking help for his hearing loss, but when confronted by a vision loss, he was unwilling to use a white cane. He indicated that he worried what message the cane use would send to co-workers. Although more than half of individuals 65 years and older have more than one chronic condition (Wolff, Starfield, & Anderson, 2002), contemporary ageing research predominantly characterizes and formulates treatments for distinct impairments. Few attempts have been made to address the needs of individuals with multiple morbidities. Moreover, there is limited understanding of the added burden of multiple stigmas (Conner & Rosen, 2008).

The stigma-induced identity threat model also serves to identify new avenues of research. For example, a question that arose during analyses was how a dramatic change in a person's hearing loss (i.e., box c, personal characteristics) may fit into the stigma-induced identity threat model. With increasing regularity, older adults are eligible to receive a cochlear implant. For many people, this technology offers a transition from a life with little or no residual hearing (i.e., deafness) to a life with a moderately-severe or severe hearing loss. Thus, over the years an individual could conceivably move from being a person with normal hearing, who can easily participate in social exchanges (i.e., an outsider), to being a person with a profound hearing loss, for whom social exchanges are difficult or impossible (i.e., an insider), then, after implantation back to being someone who can participate in social exchanges (i.e., an outsider once again). Studies seeking to understand the experience of moving into and out of group membership do not exist.

## Discussion of methodological choices

The findings of this dissertation should be considered with an understanding of the some of the key methodological decisions. An important limitation of this dissertation is the import placed on interviewing in data collection. In hindsight, a more balanced data collection strategy that incorporated a more diverse assortment of data collection techniques may be warranted to more fully understand and describe this complex field of study. For example, hearing loss stigma was found (and is theorized) to be a phenomenon that plays itself out in social settings. One can therefore imagine the contribution and value of participant observation. In future studies, participants could be followed and observed in everyday activities where stigma occurs. Moreover, given that documentation and analysis of environmental influences (architectural, public policies, etc.) would have provided a more comprehensive understanding of this phenomenon. While this level of involvement is not always possible, complex issues such as stigma demand a broad and far-reaching investigation.

Another limitation of the present studies is that they were conceived and executed by an (albeit reasonably well informed) outsider. One of the key precipitating aspects of social stigma is that it is difficult for outsiders to understand insiders. There are some who suggest that stereotyping and the development of prejudicial attitudes is the result of outsiders attempting to understand (i.e., categorize) insiders. Thus, the questions and follow-up questions posed during the interview process, the analyses of transcripts and interpretations of findings were all executed through the lens of someone who presumably does not truly understand what it is to have a hearing loss. While some contend that investigators who have a limited knowledge of the subject under investigation since they will not be influenced by previously acquired knowledge, one might also predict benefits of insiders being part of a research team that is investigating their peers. For example, a simple example of this kind of benefit is the “focus group effect”, whereby focus group participants have been known to open up with other group members and divulge otherwise unattainable information. The explanation for this effect is that there is a deeper understanding between (presumably somehow homogenous sample of) focus group members, than that that exists between the participants and the moderator. This unspoken bond brings about a more meaningful discussion of the research topic. Presumably, one might witness similar effects by involving participants in all aspects of the research process.

As noted in the peer-support study, there are two limitations of qualitative description studies. First, studies that employ retrospective interviewing risk that participants may have poor recall of relevant experiences. While this would not normally be a concern as participant memories of events are in fact their subjective reality, this was a concern for the study presented in Chapter Three. For this study, we recognized that that participants may have had a tendency to provide (relatively speaking superficial) proverbial narratives learned in peer group meetings. While this information is relevant (as it is also a subjective experience), efforts were made by the interviewer to seek more in-depth narratives. The interviewer was adept at identifying material learned in peer-support groups, and was prepared to redirect the respondent toward more meaningful narratives. In the workplace study we employed an innovative technique called Photo Elicitation Technique, for this very reason. This technique that involves the interviewer presenting a series of images to the interviewee with the intent of provoking a response, evoking memories and extracting information has been found to improve recall of previous events and in general stimulated communication.

Second, the findings of these studies should not be considered representative of all people who acquire hearing loss in adulthood. Comparatively small samples were selected in order to provide information rich data relevant to the purposes of the studies. The participants in these studies were exceptional in that they were willing to be interviewed about their hearing loss and their experiences with stigmatization.

## Conclusion

The purpose of this thesis was to characterize and better understand how people with acquired hearing loss adapt to and manage this chronic disability in light of challenges presented by social and self-stigma. Prejudicial attitudes present in North American society bring about important challenges for individuals who have hearing loss. Hearing loss stigma can cause social isolation, depression and serves as an important barrier to individuals seeking out and taking up rehabilitation services.

This dissertation sought to characterize the nature of hearing loss stigma. Specifically, the purpose of the first investigation was to apply a contemporary theoretically grounded conceptual model of the stigma process to the case of acquired hearing loss. Two studies were undertaken to describe stigma's impacts on two important activities for persons with hearing loss, namely help-seeking and revealing hearing loss in the workplace.

A central component of this dissertation has been the use of qualitative description. The objective of qualitative description studies is to provide a comprehensive summary of participant experiences presented in everyday language without high-level interpretation. The aim of using this approach was to give a voice to those individuals who are often marginalized and forgotten. This approach served its purpose.

Hearing loss stigma is a powerful societal phenomenon. Stigmas firmly ingratiate themselves into the fabric of institutional and social structures. The persistent and unyielding nature of stereotypes presents important challenges to people who acquire disabilities in adulthood as well as for health care practitioners who serve these individuals. As a society this is an imposing challenge to find ways to decompose prejudicial attitudes. This dissertation contributes to this discussion by broadening the understanding of hearing loss stigma through the application of the stigma-induced identity threat model to the case of acquired hearing loss, by exploring stigma as applied to revealing hearing loss in the workplace, and by examining the two sides of stigma as it relates to help-seeking.

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# Appendix 1: Consent form – article 2

| | | |
|---|---|---|
| Université de Montréal<br>Faculté de médecine<br>École d'orthophonie et d'audiologie | CRIUGM<br>Centre de recherche de l'institut universitaire de gériatrie de Montréal | CHIP<br>Communicaid for Hearing Impaired Persons |

## CONSENT FORM FOR MY PARTICIPATION IN A RESEARCH PROJECT – (USER OF HEARING ASSISTANCE TECHNOLOGIES)

I, the undersigned ____________________, hereby consent to participate in the following research project, according to the conditions described below.

**Project title:**
Factors that influence hearing assistance technology use by older adults

**Persons in charge:**
Kenneth Southall, M.Sc. (Doctoral Student, Université de Montréal)
Jean-Pierre Gagné, Ph.D.(Professor, Université de Montréal)

**Preamble**
My participation in this study is entirely voluntary. I understand that I should read the information below, and ask questions about anything I do not understand, before deciding whether or not to participate.

**Presentation of the project and objective:**
I have been asked to participate in a research study conducted by researchers from the School of Speech Language Pathology and Audiology at the University of Montréal. I have been asked to participate in this study because I am a current user of a hearing assistance technologies, I am 65

years of age or older, have a moderate hearing loss, live at home and I am English speaking.

Relatively few older adults who have a hearing difficulties use hearing assistance technologies (HATs) to aid them in daily activities. Studies have shown that HATs are under-used, but we do not understand why. This study will solicit the opinions of older adults who have a hearing loss and use HATs, older adults who have a hearing loss and do not use these devices, the spouses of users, Audiologists, hearing aid distributors, representatives of companies who manufacture these technologies and support group volunteers to try to better understand the factors that influence older adult's use of hearing assistance technologies.

**Nature and length of my participation:**
If I volunteer to participate in this study, I understand that I will be expected to participate in a recorded focus group discussion. This discussion will last approximately 90 minutes. During this focus group I will be asked about the following subjects: (i) the consequences of my hearing loss, (ii) the factors that influenced the purchase and utilization of hearing assistance technologies, (iii) my opinions about hearing assistance technologies, (iv) and other related topics.

**Possible advantages resulting from my participation:**
I will not derive any direct advantage from my participation in this research project other than contributing to the advancement of the knowledge of hearing assistance technologies.

**Possible risks and inconveniences resulting from my participation:**
Participation in this research involves no known risks, but I may experience discomfort if discussing the subjects listed above is considered a sensitive or personal matter. If I experience discomfort, the primary researcher is prepared to refer me to an appropriately qualified employee at the MacKay Center. I may consider the time required to participate in this research project an inconvenience.

**Information concerning the project:**
I understand that the researchers will respond to my satisfaction all questions concerning this project.

**Withdrawal from the project:**
My participation in this research is voluntary. If I choose not to participate, this decision will not affect my relationship with the MacKay Center. If I decide to participate, I am free to withdraw my consent and discontinue participation at any time without prejudice. In case of my withdrawal from this research project the audio-recordings and transcripts concerning me could be destroyed at my request.

**Interruption of the project by the researcher:**
I understand that this research project may be stopped by the researchers, at any point, for circumstances unknown.

**Access to my Audiology file:**
I accept that the persons responsible for this project are going to have access to my Audiology file.

Yes ☐ No ☐

Name of physician: ______________________________

Address: _________________________________________________________

_________________________________________________________

Name of Audiologist: ______________________________

Address: _________________________________________________________

_________________________________________________________

**Confidentiality:**
Personal information (name, address, or any other information) that concerns me will be kept confidential within limits under the law. Information about me will be coded and kept in a locked filing cabinet (in the laboratory of Dr Jean-Pierre Gagné at Institut universitaire de gériatrie de Montréal) to which only the above-mentioned researchers will have access. Additionally, all of the data (including the audio recordings) will be kept for five 5 years then destroyed after this period of time. In the event that the results of this project

are presented or published, no information will be included that would reveal my identity.

One exception will be made in the case where my file needs to be reviewed by the research ethics committee at Institut universitaire de gériatrie de Montréal, or by organizations that fund or have commissioned this research. The members of these committees are held to respect the requirements of confidentiality.

As a participant in this project, I am expected to keep confidential all information that I hear during the focus group sessions concerning other participants.

**Access to the researchers**

If I have any questions regarding the research project, I understand that I am free to contact any members of the research team.

**In case of complaint**

If you have difficulties with, or wish to raise concerns about your participation in this research project, you can, after having discussed these matters with the research team, contact the person responsible for complaints at the Institut universitaire de gériatrie de Montréal at the following address: l'Institut universitaire de gériatrie de Montréal, 4565, chemin Queen Mary, Montréal (H3W 1W5).

**Information on ethical surveillance**

The ethics committee for research at the Institut universitaire de gériatrie de Montréal has approved this research project, and assures that respect for ethical standards will be followed during all phases of this project. For more information, you can contact the secretary of the ethics committee for research at the Institut universitaire de gériatrie de Montréal at (514) 340-2800 extension 3250.

## SIGNATURE OF RESEARCH SUBJECT

I have read (or someone has read to me) the information provided above. I have been given an opportunity to ask questions and all of my questions have been answered to my satisfaction. I have been given a copy of this form.

**BY SIGNING THIS FORM, I WILLINGLY AGREE TO PARTICIPATE IN THE RESEARCH IT DESCRIBES.**

____________________________________

Name of Subject

____________________________________ ____________

Signature of Subject Date

____________________________________

Name of Witness

____________________________________ ____________

Signature of Witness Date

## SIGNATURE OF INVESTIGATOR

I have explained the research to the subject and answered all of his/her questions. I believe that he/she understands the information described in this document and freely consents to participate.

_________________________

Name of Investigator

_________________________ _________________________

Signature of Investigator Date (must be the same as subject's)

***Last revised:9:38 AM 1/17/11***

# Appendix 2 : Consent form – article 3

Université de Montréal
École d'orthophonie et d'audiologie

Centre de recherche
iugm
Institut universitaire
de gériatrie de Montréal

## INFORMATION AND CONSENT FORM

### Information section

### TITLE OF THE RESEARCH PROJECT

Stigma and disclosing (or not) one's hearing loss in the workplace: The strategies used by people with hearing loss.

### PRINCIPLE INVESTGATOR

**Jean-Pierre Gagné, Ph.D.**
Chercheur, CRIUGM
Professeur, École d'orthophonie et d'audiologie
Université de Montréal
Montréal (Québec) H3C 3J7

### CO-INVESTIGATORS

**Mary-Beth Jennings, Ph.D.**
Researcher, National Centre for Audiology
Professor, Dept. of Communication Sciences and Disorders
The University of Western Ontario
London, ON, Canada N6G 1H1

### RESEARCH FUNDED BY

This research project is funded by the *'Hear-the-World Foundation'* which is an international foundation that is sponsored by Phonak, a hearing instrument company based in Switzerland.

### PREAMBULE

We are requesting your participation in a research project. However, before agreeing to participate in this research project, please take the time to read, understand, and consider carefully the following information.

Your participation in this research project is completely voluntary. You are free to refuse to participate.

This document was approved by the *Comité d'éthique de la recherche de l'IUGM*, on July 29th 2008 (n° de référence : 2008-0604)

This information document and consent form explains the goal of the research project and the procedures that will be used for the investigation. Also, it provides a description of the advantages, the risks, and the inconveniences that may be associated with your participation in the project.

The information document and consent form may contain words that you will not understand. If so, we invite you to ask any questions to the investigator or to the members of the research team that are involved in the project. They will explain or clarify any words or information that is not clear to you.

## MAIN OBJECTIVES OF THE RESEARCH PROJECT

In many societies negative stereotypes and prejudices are attributed to people who have hearing loss. Partly because of society's view of deafness many individuals who have hearing loss are stigmatized. Hence, their social identity (how they perceive themselves) is altered due to society's perceptions and due to their own conscious (or unconscious) prejudicial views of hearing loss. This phenomenon, known as stigmatization, is very prominent in our society.

Because the presence of hearing loss is not visible, some individuals may choose to conceal, deny, or minimize their hearing impairment. A variety of strategies are used to conceal hearing impairment from others. Clinical experience and research reports have shown that some people choose to conceal their hearing loss in the workplace while others may choose to disclose their hearing loss in their worksetting. At the present time, the effects of concealing (or disclosing) hearing loss in the workplace are not well documented. We are conducting a research project in order to gather information about the stigma associated with hearing loss and the consequences of concealing or disclosing one's hearing loss in one specific setting namely, the workplace. The goals of the research project are:

1. To develop a better understanding of the factors involved in deciding to conceal or disclose one's hearing loss in the workplace.

2. To describe the consequences (positive, negative, or neutral) of concealing or disclosing one's hearing loss in the workplace.

## NATURE OF YOUR PARTICIPATION IN THE RESEARCH PROJECT

If you agree to participate in the research project you will be ask to take part in one personal interview that will be conducted in the conference room of CHIP (Communicaid for hearing Impaired persons) located at 3500, Décarie Blvd, Montréal, Québec. All the participants will have a hearing loss acquired in adulthood (after the age of 20 years), be able to speak and understand English fluently, be actively involved in remunerated work outside the home for at least 20 hours a week, and have at least one other colleague who works in the same workplace. Also, we will only consider participants who do not have any physical traits that may be considered stigmatizing by you or others.

You will be asked to sign a release form that will allow the investigators to obtain the results of your most recent audiological evaluation from your audiologists and from your hearing aid dispenser. This information will allow the researchers to document the type and severity of your hearing impairment as well as provide information concerning the type of hearing amplification you use, if any. In addition, you will be asked to fill in a short questionnaire about the type of work you do. This information will serve to document what type of employer you work for (e.g. a bank, a retail store, etc.) and the type of work you perform. It will also make it possible for you to describe your work environment. Finally, if you wish, you will be fitted with a FM-amplification system for use during the interview. This type of portable device optimizes hearing.

Once the meeting begins, the interviewer will ask a series of questions concerning how you deal with your hearing loss in your work setting. Some questions are likely to touch on specific situations like what happens during telephone conversations, one-on-one meetings with a superior, group meeting, conversations in the lunchroom, and work related social gatherings. However, you will be invited to share any experiences related to your hearing los in the workplace that you deem appropriate and important to convey to the interviewer. If you like about 45 – 60 minutes after the interview has started you may take a short break. The interview will resume about 10 – 15 minutes later. At the end of the meeting you will be asked to hand-in the FM-amplification system, if you have borrowed one.

All the discussions held during the interview will be audio recorded. This is done so that, after the meeting the research team can transcribe everything that was said during the interview. The transcriptions will be used to summarize the important issues raised during the interview. Note that your name will not the used in the transcriptions. Instead you will be identified by a special number-code that only the researchers will know. In that way everything that you wish to say will remain anonymous.

Once the content of the interview has been transcribed, you will have the opportunity to read a summary of the issues that were discussed. A member of the research team will contact you by telephone or by email and arrange for the summary report to be sent to you. At that point, if you wish, you will have the opportunity to make any comments concerning the topics discussed during the interview.

## POSSIBLE RISKS RESULTING FROM YOUR PARTICIPATION:

To our knowledge, participating in this project will not encompass any risks whatsoever.

## POSSIBLE INCONVENIENCES RESULTING FROM YOUR PARTICIPATION

Participating in this research project involves a commitment in time. In addition, it is possible that you may experience some fatigue, some frustration, and some stress as a result of taking part in the interview.

## BENEFITS PROCURED AS A RESULT OF PARTICIPATING IN THE RESEARCH PROJECT

There are no direct advantages or benefits associated to participating in this research. However, the results of the investigation will contribute to the advancement of knowledge concerning the physical, psychological, and emotional adjustments that people with hearing loss may have to make in their work environment.

## COMPENSATION

You will be given a $20.00 (twenty dollars) stipend for your participation.

## PARTICIPANT'S RIGHTS

Should you experience any prejudice or should there be any health consequences attributable to your participation in the research project, you will be provided with all the health care required, at no cost to you.

By taking part of this project, you do not forfeit any of your legal rights nor do you release the researchers, the sponsor, or the establishment of any of their civil and professional responsibilities.

## VOLUNTARY PARTICIPATION AND WITHDRAWAL FROM THE PROJECT

It is understood that your participation in this research project is completely voluntary. You are free to refuse to take part in the project. Furthermore, you may withdraw from the research project at anytime you choose. You do not have to provide any justification for withdrawing your participation; you simply have to inform the investigator of your decision.

## TERMINATION OF PROJECT BY THE RESEARCHER

The investigators, the funding agency or the research ethics committee of the *IUGM*, may terminate your involvement in the research project without your approval for scientific or technical reasons or for any of the following reasons:

- If you do not follow the instructions given concerning the research project;
- If the principle investigator thinks that it would be in your best interest to withdraw from the study;
- If there are administrative reasons to suspend the project.

## CONFIDENTIALITY

During the course of your participation in this study, the investigators and the research personnel will collect and record all information that concerns you in a research file. Only information specifically needed for this study will be collected.

This information may include your lifestyle, habits and other information such as your name, gender and date of birth and ethnic origin. Also information concerning your hearing loss and any amplification system you may use will be collected. Furthermore, some information concerning you worksetting will be collected.

All of the information collected during the course of the study will remain strictly confidential, within the limits specified by the law. In order to protect your identity and the confidentiality of this information you will only be identified by a code number. The key of the code linking your name to your research file will be kept by the principle investigator.

The principle investigator will use the study data for research purposes in order the meet the scientific objectives of the study as described above in the section 'Main objectives of the research project'. Your personal information will be destroyed 5 years after the end of this project. Specifically, the paper documents will be shredded and the audio tapes will be erased.

The data from this study may be published in scientific or professional journals or shared with other persons during scientific discussions. No publication or scientific communication will disclose any information that would allow you to be identified.

For monitoring and control purposes, your research file may be consulted by a person designated by the *Comité d'éthique de la recherche of IUGM*, by a person designated by the minister of Health and Social Services, by authorized governmental health authorities, and by representatives of the sponsor. All of these persons and organizations observe a policy of confidentiality.

For protection purposes and in order to contact you quickly, your name, address, phone number as well as the beginning date and the ending date of your participation in the project will be conserved by the principal investigator in a repertory for one year after the completion of the project.

You have the right to consult your research file to verify the correctness of the collected information, to have out-of-date or unjustified information corrected or deleted, and to make copies, for as long as the principle investigator, the establishment, or research institute possess this information. However, in order to preserve the scientific integrity of the study, you will not have access to some of this information until the study is completed.

## SOURCE OF FUNDING FOR THE PROJECT

The investigators were awarded a grant from the Hear-the-World Foundation to conduct the present project. All the costs and expenses pertaining to this research project will be covered by that grant.

## DISCLOSURE OF ANY NEW INFORMATION

Any new information obtained during the course of the project that could have an effect on your decision to continue participating in the research project will be communicated to you immediately.

## PERSONS TO REACH

If you have any questions related to the research project or to the terms of involvement please contact Jean-Pierre Gagné, Ph.D., in any of the following ways: 1- by telephone: [redacted], by fax: [redacted] by email: [redacted]

For any questions related to your rights as a participant in this research project, or if you have any complaints or comments to make, please contact the person responsible for complaints at the *IUGM*. That person may be reached as follows: Local Commissionaire of Quality Services, IUGM, 4565, chemin Queen-Mary, Montréal (Québec) H3W 1W5. Tel.: (514) 340-3517.

## INFORMATON ON ETHICS

The research ethics committee of the *IUGM* has approved this research project and guarantees its follow up. In addition, the ethics committee will approve any modification made to the information and consent form as well as to the research protocol itself. For more information call *the Secrétariat du comité d'éthique de la recherche de lIUGM*, at 514 340 3800 #3250.

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## Consent form section

### PARTICIPANT'S CONSENT

I declare that I have read this information and consent form. I acknowledge that the investigators have explained to me the research project, answered all my questions and gave me all the time I required to make a decision concerning accepting or not.

I consent freely and voluntarily to participate in this project. I will be provided with a sighed copy of this information and consent form.

____________________________ ________________

Name and signature of the participant Date

### INVESTIGATOR'S DECLARATION

I certify having explained to the participant the terms of this information and consent form, that I have answered all the questions that the participant had related to the research and that I clearly pointed out that he/she is free to put an end to his/her participation without prejudice and that I commit myself to respect what has been agreed to in the information and consent form.

________________________________ __________________

Name and signature of the researcher Date

# Appendix 3: Workplace questionnaire

## Stigma and Disclosing (or not) One's Hearing Loss in the Workplace: The Strategies Used by People with Hearing Loss

### Workplace Questionnaire

1. Please describe your current employer.
    a. Approximate number of employees?
    b. Reporting structure within your department?
    c. Type of employer?
    d. Are supports for accommodations available?
2. Please describe your work setting.
    a. Is your work mainly indoors or out of doors?
    b. Describe the physical environment in which you work. Where is your main work area located related to where others sit, noise levels, placement of equipment such as computers and photocopiers/fax machines.

   c. Does your job require you to change environments on a regular basis? If so, please describe these environments.

3. Please describe the communication demands of each of your responsibilities in the workplace. Describe the situations in which you communicate where difficulties with communication occur.

   a. What problems with communication cause you stress or impact on your job performance?

   b. Does your job require you to attend meetings? If so, how often and for what purpose(s)? How many people are in attendance? How often do they happen? Are the formal or informal? In-house, out of the office, in restaurants? Describe the physical layout of the meeting space and where you normally sit. Do you use any hearing assistive technologies to help you to hear in meetings?

c. Do you use the telephone on a regular basis? Do you have any special equipment to assist you to hear on the telephone?

d. Does your job require you to travel? What accommodations are made when you fly, stay at a hotel, conferences, meetings outside the office. Do you use any hearing assistive technologies to help you to hear when you are away from the office?

e. Other:

# Appendix 4: Codes, definitions and representative excerpts – article 2

| Code | Information regarding… | Representative excerpt |
|---|---|---|
| | | |
| Adaptations to HL | awareness of HL, acceptance of HL and readiness to seek help for HL | *I really didn't realize it. I had no clue what so ever. None. I guess it sort of seeped away bit by bit.* |
| | | |
| Emotions | feelings about own hearing loss and efforts to seek help for hearing difficulties | *I have learned that there is nothing to be ashamed of. It is not something that you have to hide.* |
| | | |
| Environment – physical / social | the interaction between the physical / social environment and the respondent's help seeking | *I feel that when you get to the Midwest, unless you are in the city, a lot of the people are not as progressive thinking [about HL]* |
| | | |
| Individual responses | adaptive / maladaptive, and conscious / unconscious efforts to manage HL | *It was very isolating, but I think I made up for it by being very gregarious, outgoing and curious.* |
| | | |
| Outcome | the effect of help seeking - influenced by social and/or self-stigma | *I am not the shy and reserved person that I was. I [now have] a self-confidence and self-worth that I could never buy.* |
| | | |
| Peer-support group | volunteer activities, respondent's fit within group and role of colleagues in help seeking | *The first thing that happened, what always happens when you get involved with an organization that caters to your needs, you* |

| | | |
|---|---|---|
| | | *don't feel like you are a minority, and you begin to relax. And this makes you understand more.* |
| | | |
| Personal characteristics | attributes inherent to respondent that influences help seeking | *I am a very pigheaded stubborn person.* |
| | | |
| Referrals to seek help | information about help seeking | *Some newspapers are writing quite regularly on hearing issues. These walks for hearing, have you heard about them?* |
| | | |
| Stigma | incidents of discrimination because of hearing loss | *How many people go to the hospital, are unable to hear, and suddenly they are being asked "do you know who the prime minister is, dear?"* |
| | | |
| Stigma – elements of situation | specific aspects of stigmatizing events | *There was no email or fax at that time. I would sweat. I would just sweat during a telephone call.* |
| | | |
| Stigma - dimensions | disclosure / concealing, being outed, labels, visibility of stigma, power dynamic | *I think I realise more [and more] how helpful my colleagues will be if I'd just ask for help.* |
| | | |
| Stigma - self-stigma | application of prevalent stereotypes to self | *I was always blaming myself for not listening properly and for not paying more attention. I criticized myself. You know, "come on, snap out of it dear!"* |
| | | |
| Stigma - stereotypes | commonly held and overly simplified beliefs about people who | *They will think that I'm not capable. It is still the stigma that ties hearing loss to a lack of* |

| | | |
|---|---|---|
| | have HL | *mental agility.* |
| | | |
| Stress | psychological and physical stress associated with social and physical environment | *It is a source of stress. Since I am retired I got rid of some stresses, so I have time to deal with others. I have learned.* |
| | | |
| Triggers to seek help | specific people, beliefs, information or events that prompt help-seeking | *The necessity for me is trying as many different things as possible to keep living in a healthy way. To keep participating in human communications, in spite of my hearing loss.* |

# Appendix 5 : Participant information – article 3

| **Pseudonym (Gender: M = Male; F=Female)** | **Age** | **Self-reported level of hearing loss** | **Hearing technology; Workplace accommodations** | **Occupation (years at post/company)** | **Description of workplace duties and work environment** | **Demanding communication in workplace** |
|---|---|---|---|---|---|---|
| Mike[1] (M) | 43 | Moderate-severe | Behind-the-ear hearing aids (2) | Engineer (12 yrs at post) | Very large company, cubicle, meetings; variable level of noise | Two people talking at once; teleconferencing; large noisy environments |
| Julie (F) | 54 | Moderate | Behind-the-ear hearing aids (2), adapted telephone | Buyer (35 yrs with company) | Large company, personal office; often speaks on telephones sometimes attends meetings in other parts of building | Concentrating for lengthy meetings; accents |

| | | | | | | |
|---|---|---|---|---|---|---|
| Zola (F) | 60 | Moderate | In-the-ear hearing aids (2) adapted telephone with headset | Social worker (35 yrs with company) | Medium sized organization; shared office; frequent home visits with clients; telephone calls; meetings | Background noise; soft talkers; telephone work |
| Janice (F) | 62 | Moderate-severe | Behind-the-ear (1), In-the-ear (1) hearing aids | Hotel manager (sales) | Medium sized organization; shared office; sales meetings in dining room | Meetings; sales meetings in noisy dining room |
| George (M) | 64 | Mild | Behind-the-ear hearing aids (2) | Academic counselor at a college (20 yrs) | Large institution; personal office; meets with students; some noise from neighboring offices; some small group meetings elsewhere in building; telephone calls | Soft talkers; more than one person speaking at once |
| Diane (F) | 64 | Moderate Tinnitus | In-the-ear hearing aids (2), adapted telephone | Family physician/researcher (38 yrs family physician; 2 yrs research group coordinator) | Small department; personal office; some student supervision; frequent small meetings; attends national | |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | | | international conferences | |
| Lisa (F) | 58 | Profound | Cochlear implant, many adaptive technologies | Federal government employee (5 yrs) | Open concept office space; noisy; many meetings small to medium in size | Teleconferencing; meetings |
| Larry (M) | 54 | Profound | Cochlear implant, many adaptive technologies | Programs supervisor - Non-profit charity (1 yr) | Small organization; personal office; quiet; communication via email/skype; some conference travel; meetings varying in size once a month | Unexpected unsolicited phone calls; burden of email dependency |
| Leslie (F) | 52 | Profound | In-the-ear hearing aids (2), FM system, adapted telephone, real-time captioning | Lawyer (17 yrs) | Large public sector department; quiet environment; personal office; boardroom meetings; conference travel | Disorderly meetings of all sizes; malfunctioning adaptive aids; availability of real time captioning |
| Eric (M) | 73 | Moderate (right ear)<br>Moderate-severe | Behind-the-ear hearing aids (2) | High school teacher (2 yrs); journalist (25 yrs); Factory manager (10 yrs); Driver - car, rental company (7 yrs | Factory – personal office; meetings; travel (US)<br>Car rental company - medium sized | Noise on factory floor<br>Noise while driving passengers (radio, talking, wind, traffic); |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | (left) Tinnitus | | at current post) | organization; mostly work outdoors on or in cars, trucks; informal office meetings of 2-6 people | Hearing instructions;<br>phone calls;<br>communicating with his female managers |
| Gary (M) | 68 | Moderate-severe | In-the-ear hearing aid (1), telephone with telephone | Engineering consultant - (10 + yrs); business consultant; Electronics Company – designing and developing steel service centres;<br>Property Management Company – Procurement Manager | Engineering - Large institution; plant office and personal office; meetings; international travel; Consultant - phone calls; traveling sales<br>Electronics – large organization, cubicle; plant visits; international travel<br>Property Management – cubicles (5-6 people) | Background noise;<br>mumbled conversations;<br>boardroom meetings;<br>business conversations in airports, restaurants;<br>conversations in cubicles |

| | | | | | | |
|---|---|---|---|---|---|---|
| Brian (M) | 55 | Moderate Processing problem | Behind-the-ear hearing aid (1) | Wood processing plant (2 yrs); Fruit processing plant (2 yrs); Car rental agency (wash bay, office)- current; Airport transport service to/from an international airport – current | Small organization; wash bay, inside vehicles, front office; delivery/pickup of vehicles, customers within city | Plants – background noise; lunchtime conversations<br>Car company - conversations in wash bay (noise, echo); following instructions, noise in office area (phones, conversations)<br>Transport Service – conversations with passengers, dispatcher (cell phone); one-on-one conversations in the office |