Towards a Social Psychology of Living With Acquired Hearing Loss

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Abstract

Stigmatized social identity can create psychological barriers to the effective delivery of hearing services for people with acquired hearing loss. These barriers can lead to denial and inhibit clients from accepting the help they need, even if this denial poses disadvantages to their well-being. To overcome these barriers, services are needed that address identity-related issues along with strategies that specifically address stigma. Acquired hearing loss can disrupt existing interpersonal social relations and threaten social identity and status. Efforts to change group norms within a client's immediate social network can provide the social support and practical solutions needed to minimize distress and help create a pool of people who are capable of mobilizing in the interests of broader destigmatization and social change. From the perspective of social psychology and social identity theory, the outreach strategy in the audiologic rehabilitation program originally described by Raymond Hétu and colleague Louise Getty (Getty & Hétu, 1991; Hétu & Getty, 1991), referred to herein as the Montreal Model*, offers clinicians an effective psychosocial strategy for engaging clients and significant others in a useful change process.*

Humans are social beings who do not experience hearing-related communication problems in a social vacuum (Hogan, 2001). Hearing-related communication problems can result in the stigmatization of the person with hearing loss (Gagné, Southall, & Jennings, 2009; Hallberg & Carlsson, 1991; Hétu, 1996). As Giddens (1984) observed, stigma arises when an individual is deemed socially incompetent—in the context of hearing impairment, because he or she cannot follow the customary social rules of speaking, listening, and responding appropriately. People with hearing loss often attempt to manage stigma by avoiding practices and behaviors that would marginalize or delegitimize them.

The transition from hearing to having an acquired hearing impairment has implications for group membership. One may continue to identify with groups of hearing individuals or, over time, identify only with groups of individuals with hearing impairment (groups that are often stigmatized). Because these two groups have a different social status, questions arise about the

implications of transitioning (or resisting transition) downward in status. Thus, the choice can be to accept stigmatization or to continue to pass as hearing by denying the problem and engaging in avoidance behaviors, including not seeking help for hearing loss and not using hearing aids or hearing tactics. The social dynamics that lead people to such a choice are not inevitable. Understanding the social dimension of hearing impairment makes it possible to design interventions that address identity concerns. Evidence suggests that identifying with the lower status group, but re-envisioning this identity positively, can promote empowerment rather than stigmatization. This process is particularly effective when joining others and creating a positive definition of who "we" are, challenging the perceived status of the hearing group. Group-based redefinition and destigmatization offer a path to an enhanced social identity, social support, and opportunities for long-lasting change (Crabtree, Haslam, Postmes, & Haslam, 2010; Schmitt & Branscombe, 2002). With the support of one's immediate network, a person with hearing impairment can use hearing aids and strategies to create better hearing environments to facilitate a strategy of not only passing for hearing but also effectively participating in social exchange. Because stigma surrounding hearing loss can result in people being reluctant to participate in social interaction, proactive intervention can prevent the worst effects of stigma.

Stigma, Marginalization, and Stereotyping

Goffman (1963) wrote that "the central feature of the stigmatised individual's situation in life…is a question of what is often, if vaguely, called 'acceptance'" (p. 19). Hearing loss has carried a social stigma across millennia. In ancient Greece, deafness was seen as a curse, an absence of intelligence, and an inability to participate in community life (Rose, 2006). Through medieval times, those who were unable to understand or express speech were, by law, denied the rights of an individual. Moreover, one was not allowed to receive the sacraments of the Church, which was considered a major element of full participation in community life (Lane, 1984).

Stigma related to hearing loss is not limited to Western cultures or religion. Miles (1984) reported that in rural Asian communities, families may conceal serious hearing loss to protect relatives' eligibility for marriage and to avoid the stigma of disability, which is regarded as a punishment for parental sins or as evidence of the person's sins in a previous life. In modern Australia, Westbrook, Legge, and Pennay (1994) examined how people from different ethnic backgrounds explained disabilities such as hearing loss. In some cultures, sinfulness and loss of karma were seen as significant factors contributing to hearing loss.

Goffman (1963) argued that our expectations of social interaction are linked with notions of social status and that when a person does not behave according to expectations, "he is thus reduced…from a whole and usual person to a tainted, discounted one" (p. 12). It is this discounting of the individual that gives rise to the concept of stigma, "a societal reaction that 'spoils' normal identity" (Williams, 1987, p. 139). Persons with hearing loss quickly become aware of the negative attitudes that can arise when their behavior does not conform to community expectations. For example, in a study conducted by Hogan (1990), 20 people with severe hearing impairment who were enrolled in a lipreading group were asked to list some labels used to describe people with hearing impairment. Their responses included "deaf," "heedless," "snobbish," "inattentive," "stupid," "idiot," "not with it," "dumb," "ignorant," "useless," "retarded," "boring," "arrogant," "stubborn," "slow," "vague," and "psycho" (Hogan, 1990). Twenty years later, a similar group in the same lip-reading club reported the psychosocial consequences of these stereotypes: "I'm a nuisance," "I'm hard to include," "I don't matter," "I don't fit in," "I feel depressed," "I feel isolated," "I'm difficult," "I feel less of a person," "I am invisible," "I feel left out." Noticeably, many of these labels refer to an inability to participate in society, suggesting that even tacit exclusion by people with typical hearing may be experienced as stigmatizing.

The labels offered by respondents in the lipreading group may be extreme, and these respondents may have more severe hearing loss than an average client; nevertheless, the study results suggest that what happens at the margins of society is informative about what happens to people in the middle. People with more severe hearing loss may experience the kinds of stigmatization noted above more intensely, but people with mild and moderate hearing loss also experience such events, if to a lesser degree. Additionally, the latter group may observe what happens to people with more severe hearing loss and may seek to avoid such outcomes.

The fear of being stigmatized relates to the way a person fits in or adjusts to society's demands. As such, the concept of "fitting in" can be seen as a structuring principle (Giddens, 1984) that influences relationships at an individual level while having a direct impact on the person's social position, such as one with a physical impairment. The person's fit affects other aspects life, including stress, coping, competence, self-direction, relatedness to others, and self-esteem (Giddens, 1984, 1991). Stigma is associated with a fear of marginalization (Hétu & Getty, 1991), triggering a reluctance to acknowledge the hearing loss and efforts to conceal it. These behaviors, in turn, can lead to ongoing vigilance and high levels of stress.

Stigma and Its Relationship to Social Identity

The association of stigmatization with hearing loss–related behaviors provides evidence that hearing culture exists as a social reality or social fact, which is

> recognized by the power of external coercion which it exercises or is capable of exercising over individuals, and the presence of this power may be recognized in its turn by the resistance offered [towards] every individual who tends to violate it (Durkheim, 1971, p. 63).

Social facts often form the fabric of established practices that are unique to specific groups at certain times and places. In the context of hearing society, there is strong consensus that certain ways of interacting are regarded as normal. In this sense, the established rules and values of the hearing world constitute social facts. Group processes and associated consensus define social facts and shape perceptions and behavior (Haslam, 2004; Haslam, Eggins, & Reynolds, 2003; Haslam, Turner, Oakes, McGarty, & Reynolds, 1998). A person's perception of belonging to groups is defined, at some level, by their interaction practices. When that person has hearing loss, typical group practices are more difficult to enact. This difficulty disrupts interpersonal social interactions, putting the group member at risk for being resisted, excluded, and marginalized. Disrupting interactions with hearing tactics that require communication partners to modify their usual patterns of speaking and listening is not standard social practice. In effect, the dominant social practices inherent in hearing interactions can marginalize people who are hearing impaired.

More than a simple external sense of coercion and censure, this marginalization has flow-on effects for a person's social position and group membership. Flow-on effects occur because, at a basic psychological level, the less group members embody accepted norms and practices that define the group, the more marginalized they become. Therefore, individuals with hearing loss struggle to maintain their position in social groups.

The issues surrounding social position are, perhaps, more pronounced for those who had full-fledged "membership" in the "hearing group" but who now find this inclusion threatened due to hearing loss. Hence, identity dynamics concerning how people see themselves become important when dealing with the onset of hearing impairment. Haslam (2004), summarizing work on social identity theory (Tajfel & Turner, 1979) and self-categorization theory (e.g., Turner, Oakes, Haslam & McGarty, 1994), outlines the concept of social and personal identities

> [S]ocial identity is the individual's knowledge that he [or she] belongs to certain social groups together with some emotional and value significance to him [or her] of this group membership…social identity is part of a person's sense of 'who they are', associated with any internalized group membership. This can be distinguished from the notion of personal identity, which refers to self knowledge that derives from the individual's unique attributes (concerning physical appearance, intellectual qualities and idiosyncratic tastes) (Haslam, 2004, p. 20).

People with hearing loss who were previously members of the hearing group will have internalized (consciously or otherwise) a sense of belonging with hearing society. Because of hearing loss, they experience identity threat. Their past behavior included tacitly accepted cultural practices that reinforced the centrality of hearing in their lives. Hearing has been a fundamental part of how they have interacted in all the intimate, professional, and casual sub groupings that exist within the hearing community, and these hearing-based interactions constituted evidence that they belonged. Identification with the hearing group was valued and positive in its emotion. Conversely, people with hearing problems often resist association with the "hearing loss group" because the latter is considered a stigmatized group that does not participate in the collective behaviors of "normal" social life. Because such a group is devalued, identifying with it has emotionally negative connotations. Ties and focus remain with the hearing group as the desired group; it is the group that they were in up to the time of hearing impairment onset, and it remains the group that want to be in.

These insights provide a conceptual and practical basis for understanding why people with hearing difficulties continue to identify with hearing culture and why, in social and clinical settings, they resist implementing behavioral changes that would identify them as having hearing problems. Although representing oneself as having hearing problems may help resolve communication problems, it represents a loss of valued group membership. It is understandable that people do not want others to view them as belonging to a hearing loss group and that they resist internalizing this stigmatized group as their own social identity. The irony is that the stigma attached to hearing loss is rooted in a diminished ease of communication that can only be improved by acknowledging and managing hearing loss.

The importance of dealing with hearing loss is not simply a social issue. Hearing loss can be a stressful condition that takes a toll emotionally, mentally, and physically on the individual and his or her family members. The challenge is to develop interventions that encourage people to engage in behaviors that identify them as having hearing loss but that simultaneously minimize stigmatization, foster social support, and allow participation in broader society in order to minimize the emotional, mental, and physical toll. To address these challenges, practitioners—particularly, those in North America—have been developing audiologic rehabilitative (AR) initiatives for more than 50 years (Erdman, Wark, & Montano, 1994; Henoch, 1979; Ross 1987, 1997). A central theme of this work is the promotion of group-based programs in which mechanisms of change inherent in the group process can have a mitigating effect on problems related to identity, stigma, and well-being. Psychological adaptation to hearing impairment involves redefining and destigmatizing what it means to have hearing loss. Removing the negativity associated with the hearing loss group allows it to become one with which it is worthwhile to identify; the technologies and social strategies it affords members facilitate effective communication, thereby reducing participation restrictions. However, before such a transition can occur, it is necessary to seek social support and to challenge existing social facts and the perceived status quo (Branscombe, Fernandez, Gomez, & Cronin, 2011; Crabtree et al., 2010; Haslam, O'Brien, Jetten, Vormedal, & Penna, 2005). These points are elucidated in the Montreal Model of AR, which includes social network therapy and provides social support for the transition from an identity of "hearing" to varying degrees of "hearing loss" identity. Before considering this model, it is important to review how pressure on social and personal identity can affect well-being.

Stigma and Its Relationship to Psychosocial Well-Being

When individuals attempt to avoid being defined by an impairment or disability, their identity as part of the preferred "in-group" swings in the balance (Alston, in press; Jung, 1983), these vacillations in identity are accompanied by psychological distress, self-talk, and varying degrees of autonomic escalation. These dynamics can create psychological barriers to accepting clinical advice—hence, Hétu and Getty's (1991) observation that clients are reluctant to acknowledge their hearing problems.

Failure to relate to others as a hearing person in social settings undermines social identity and denies a person the social affirmation associated with belonging to the hearing group (i.e., all the social groups that rely on auditory communication). The predictability of everyday interactions also is lost, which further compounds identity-related social failure. Just as hearing problems render one's social identity uncertain, the loss of auditory information simultaneously renders the behaviors and motivations of others uncertain. Such uncertainty in social situations precipitates anxiety. As hearing problems continue, individuals become increasingly aware of the difficulties that they experience communicating and engaging competently. Social competence promotes feelings of pride and self-worth. Losing one's sense of competence can negatively affect psychosocial well-being. Feelings of embarrassment and shame along with hearing problems can result in withdrawal and isolation, making it difficult to address issues or live a satisfying life (Retzinger, 1996). Such withdrawal is not a conscious decision but a response driven by emotions aimed at self-protection. The perceived threat to self (the threat of stigmatization) triggers a classic fight-or-flight reaction. The threat associated with engaging in ways that put one's hearing identity at risk can result in compliance (tolerating difficult situations by pretending that everything is okay), conflict (arguing or blaming), or withdrawal (engaging in avoidance behaviors). Such reactive behaviors can become conditioned responses. Over time, clients may construe reactions to hearing difficulties to be interpersonal conflicts (Hétu & Getty, 1991) or changes in their preferred lifestyle (e.g., not enjoying going out anymore).

Well-being is affected by cognition, affect, and physiology, all of which are interrelated and vary continually in response to daily demands. More significant shifts occur when stressful events fuse thoughts, emotions, and physical responses into specific heuristic, short-cut responses to certain situations (Harris, 2009). Thus, identity dynamics affect emotional and physical dynamics and vice versa. Consistent with this idea of interconnected processes, there is evidence that people with hearing problems experience emotional and physical distress.

The wealth of material regarding the effect hearing impairment can have on well-being makes it clear that interventions are necessary on both the personal and social levels to address the communication and adjustment difficulties associated with hearing loss. Two psychosocial barriers to appropriate action that have already been identified in the audiologic literature—reluctance and misperception (Hétu & Getty, 1991)—are consistent with the social identity perspective.

Structuring Clinical Practice to Address Stigma and Its Impact on Social Identity and Well-Being

The fear of being stigmatized and losing group membership due to hearing loss manifests itself as reluctance to address hearing problems. Additionally, misperceptions of the effects of hearing loss can be manifested as denial. These two dynamics and the reactive coping strategies that may occur coalesce as substantive barriers between clients and the available wealth of clinical and technical help. To bridge the gap between the lived experience of hearing loss and the availablility of hearing help, Hétu and Getty developed the Hearing and Listening Program, referred to in Australia as the Montreal Model of Hearing Help. Hétu and Getty

designed this program to address the social aspects of accepting and coping with hearing loss problems (Getty & Hétu, 1991; Hétu & Getty, 1991). This intervention enables clients to

- overcome the dynamics of reluctance and misperception;
- develop an understanding of how hearing loss can result in interpersonal difficulties;
- access opportunities to develop skills to address their difficulties;
- experience a reduction in stigma by interacting with others who have similar difficulties;
- improve their readiness to access a broader range of problem-solving ideas for their hearing difficulties; and
- integrate hearing loss as an acceptable part of social identity by facilitating a new set of localized, in-group norms and a new social network.

Developing an effective client engagement strategy is critical to the success of the intervention. Individuals and key members of their social network should be provided opportunities to examine the impact of hearing loss on the individuals, their families, and friends; to facilitate new ways of communicating within the typical functioning of their specific family and social networks; and to develop skills to define their own needs and seek solutions to their problems.

In addition to the original articles describing the model, materials exist regarding application of the intervention (Hogan, Ewan, Noble, & Munnerley, 1994; Hogan, 2001, 2008). What is not readily available, however, is an analysis of how the materials apply to the theory identified herein and how such materials can be applied in clinical practice.

Denial and reluctance should be understood as adaptive strategies used to protect the integrity of one's identity. At a psychological level, these strategies reduce the anxiety created by a destabilized sense of self, where the self-perception of being fully hearing gradually yields to an emerging awareness of hearing impairment. Denial and reluctance are common initial responses to fear. The key for clinicians is to help clients transition through a realistic fear of being discredited because of hearing problems (Hétu, Riverin, Getty, Lalande, & St-Cyr, 1990) and to enable them to engage in a problem-solving approach. Clinicians must be sensitive to the fact that clients may not be aware of their hearing loss or may be reluctant to acknowledge they have hearing loss. Moreover, clients may not be aware that clinicians have simple, effective, and psychologically safe engagement techniques at their disposal. These techniques provide a supportive framework within which clients can initiate behavioral and identity changes with a minimized risk of anxiety about failure.

In the model, a trusted person—typically, a professional with whom the client has had prior contact—engages the prospective client in the recruitment process. During the recruitment process, the trusted person determines whether some form of communication problem exists and, if so, whether the individual has some commitment to better understanding the problem. The goal at this stage is specifically to understand the problem, not solve it. In the recruitment process, the trusted person finds an opportunity to explain the program of hearing help to the individual and his or her partner. During their meeting, the Montreal Recruitment Questionnaire (Hogan, 1992) is completed by the client and his or her partner, and then the couple is counseled regarding similarities and differences between their answers on the questionnaire. If both identify an issue as a problem, then it is documented as a problem, and the professional seeks the couple's commitment to learn more about the difficulties experienced. If neither member identifies an issue as a problem, then it is not documented as such. If only one person identifies an issue as a problem, then it is documented as such, and the professional (a) explores why one person identifies a problem whereas the

other does not and (b) seeks the commitment of the person who has not identified the problem to work toward better understanding why his or her partner identifies this issue as a problem.

This recruitment process constitutes a systematic method to address barriers that keep clients from engaging in a necessary change process. The Montreal Model is consistent with the view that the group process provides mechanisms for enabling change across the many psychosocial factors associated with hearing impairment (Erdman, 2009). These include the realization that

- one's problems are not unique or rare;
- there are options;
- others are available to help and support the change process;
- people can learn from one another and from simply observing others' behaviors;
- one can learn to view problems in new, effective ways, and
- the level of stress associated with living with hearing loss can be reduced (Erdman, 2009).

The Montreal Model extends existing work by demonstrating that specific group exercises may serve distinct functions within the change process and that clinicians must know what aspects of change they are trying to achieve when leading group activities (Hogan, 2001). To reduce the fear of stigma, early activities focus on recognizing that problems exist and that they are shared. Later in the intervention, the emphasis shifts from identification and acceptance of problems to problem solving (Hogan). The therapist's task is to enable the client to "acquire the ability to do what he or she knows should be done…to actualize an ability the person already has" (Evans, 2009, p. 43). Implemented in this fashion, the intervention enables individuals and their social groups to make room for new behaviors within their existing patterns of interaction and, in turn, affirms each person's membership within the social network. This involves a maieutic process, wherein people move from cognitive awareness of the issues toward active engagement in a process that enables them to identify the need for change themselves. Ultimately, this addresses what being affected by hearing loss means for them, their families, and their friends. The process uses practical exercises centered on "I" statements to facilitate identity change. It leads participants through the process of saying that "I" have difficulties, of identifying available social support to address their communicative needs, and role playing requests where "I" secure people's support through shared changes in behavior. In this way, participants experientially learn that their family and social networks not only want change to occur but also are willing to provide support actively. The outcome is the development of shared strategies to ensure supported participation rather than attempting to get by in a hearing group. These exercises help people integrate hearing loss into their personal and social identities.

To this end, an extension of the Montreal Model is proposed. After the follow-up visit, it would be beneficial for the service provider to facilitate a home-based discussion where other family members and key friends participate in a mini-program (e.g., an "unfair hearing test" as well as barbecue or dinner party exercises), so that they, too, can be sensitized to the issues affecting the client and learn how they can help ensure participation (Hogan, Byrne, & Reynolds, 2010). This strategy serves two purposes. Beyond educating key people in a client's social network about hearing loss, it also legitimizes changes to how people will interact in the future. This strategy incorporates hearing loss as part of the group's shared social identity, facilitating greater inclusion and destigmatization. The maieutic process once again comes into play, and close friends and family gain knowledge about hearing impairment, learning to modify their communication norms and making room for hearing loss in the way they function within their social group.

Conclusion

Managing stigmatized social identity is central to the effective delivery of hearing services because identity threats can have a cascading effect on well-being. Psychological barriers related to the fear of stigmatization can inhibit clients from accepting the help they need. The outreach strategy within the Montreal Model, which is based on social psychological theory, provides clinicians with an effective strategy for engaging clients and significant others in a beneficial and productive change process.

An understanding of identity dynamics with respect to hearing loss is informative in a number of ways. First, it helps explain why people with hearing impairment deny their circumstances and avoid treatment. Further, with the provision of social network therapies such as the Montreal Model, it is possible to see how hearing services can allow people to live better lives and participate more effectively in social situations, despite not belonging to a "fully hearing" group. Instead, a proactive communicator with hearing loss challenges the social fact of hearing-based interaction. By finding ways to participate in social groups, prospective clients help destigmatize hearing impairment and redefine localized communication norms.

The goal of group intervention is to facilitate a successful transition to identifying oneself as hearing impaired without stigma. It achieves this goal by creating a group setting where people work together to generate localized normative practices that emotionally and practically support clients' social functioning and well-being. Furthermore, a shared identity emerges among clients in the program. This identity is a basis for providing, receiving, and benefiting from social support. It provides individuals with the emotional, intellectual, and material resources to resist (i.e., question, challenge, and oppose) the stigmatization they may experience and/or fear. It also provides a broader network of people who are ready to engage in processes of rejection and modification of negative stereotypes, a process that may become increasingly important in countries with aging populations.

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