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## Is There a Culture of Hard-of-Hearing Workers?

### *Y-a-t-il une culture des travailleurs malentendants?*

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#### **Abstract**

The *Groupe d'acoustique de l'Université de Montréal* has pursued a research program on the description of the experience of hearing difficulties, especially among noise-exposed workers. Data collection included questionnaires, individual interviews, couple interviews, group interviews with couples, and focus groups with workers. The data clearly converge to show that (a) the stigma associated with hearing loss governs the method of coping and (b) the process of problem-solving depends on, in most of the cases, the support of the workers' spouses. This contrasts radically with the experience of women with an acquired hearing loss, who have no support from their husband and only a little from their peers. The main implications of these findings are: (a) because of the reluctance to disclose their hearing loss, hard-of-hearing people do not develop a culture of their own, and (b) people's experience with hearing difficulties and their search for solutions is strongly modulated by the prevailing culture to which they belong. As a consequence, audiological intervention should be modulated accordingly.

#### **Abrégé**

*Le Groupe d'acoustique de l'Université de Montréal a développé un programme de recherches qui vise à décrire les expériences de difficultés d'audition telles que vécues par les travailleurs en milieux bruyants. La collecte de données a été faite par voie de questionnaires, d'entrevues individuelles et de couples ainsi que d'entrevues de groupes de couples et de groupes de travailleurs. Les données démontrent clairement que (a) le stigmate associé à la perte auditive gouverne la façon dont on s'accommode aux difficultés d'audition et (b) le processus de recherche de solutions à ces difficultés suppose, dans la très grande majorité des cas, l'appui de la conjointe. Ce dernier résultat est radicalement différent de l'expérience des femmes qui ont une surdité acquise, lesquelles n'ont aucun appui de leur conjoint et peu de soutien de leurs pairs. Les principales conséquences de ces résultats sont les suivantes: (a) à cause de la difficulté à révéler leurs problèmes auditifs, les personnes malentendantes n'arrivent pas à se créer une culture à laquelle elles peuvent s'identifier et (b) l'expérience des difficultés auditives et la recherche de solutions est fortement marquée par la culture à laquelle appartient ces personnes. L'intervention audiolinguistique devrait donc être adaptée en conséquence.*

What is culture? Anthropologists say that it is the entirety of social structures—work, artistic, religious, and intellectual manifestations—that define and distinguish one social group from another. Accordingly, do hard-of-hearing workers have a culture? The *Groupe d'acoustique de l'Université de Montréal* has tried, over the last decade, to understand and describe the attitudes and behaviours of industrial workers who have a noise-induced hearing loss. Emphasis in the work of the acoustics group was put on the analysis of the discourse of workers, heard during interviews with individuals, groups, and couples (Getty & Hétu, 1991; Hétu, Lalonde, & Getty, 1987; Hétu, Riverin, Getty, & Lalonde, 1990; Hétu & Getty, 1991; Hétu & Getty, 1993). The findings give us clues that help us answer the question of whether or not hard-of-hearing workers have their own culture. To answer this question, we will (a) describe the differences between certain behaviours in deaf versus hard-of-hearing people; (b) describe typical attitudes and behaviours of hard-of-hearing workers, using their own discourse; and (c) analyze the perception of hearing difficulties among hard-of-hearing workers. Convergence between these lines of evidence will then be further examined.

#### **Deaf Versus Hard of Hearing**

The situation of hard-of-hearing people is very different from that of people who are born deaf or who become deaf at an early stage in life. Deaf people are identified at a very young age and most of them benefit from special education programs and resources. Most of them share a common language—sign language. As a result, their deafness is brought into the open and made visible to them and others, and their culture is defined.

In contrast, most hard-of-hearing people develop hearing impairment during adulthood. Their hearing loss generally progresses insidiously, and unless they wear a hearing aid, their condition is invisible to others. Knowing that only a fraction of those with hearing impairment seek professional help and use technical devices, a minority

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identify themselves as being hard of hearing and participate in a common set of activities. Moreover, the typical manifestations of an acquired hearing loss are often highly ambiguous. This is especially true with loss of frequency selectivity, which results in inability to understand what is being said when there is a competing sound. When the acoustic conditions are not ideal, as is frequently the case in our urban and industrial society, hard-of-hearing people have serious difficulties following group conversations although they can often understand little secrets that are told behind their back in quiet surroundings. To other people, this is very misleading. This is illustrated by a very common complaint from the wives of workers we have interviewed, namely: "he understands when he wants to..."

As a consequence, the manifestations of hearing difficulties are very often misinterpreted as a social problem ("he is not being sociable; he hates to go out"), a psychological problem ("he does not want to talk; he is edgy; he wants to isolate himself"), a relational problem ("he doesn't want to talk to me; maybe he doesn't love me anymore"), or even a cognitive problem ("he does not understand; maybe he is becoming old").

According to the findings from the National Study of Hearing conducted in the UK (Davis, 1989), one adult out of six has a hearing impairment sufficient to limit his or her activities. However, only 20% of these people seek professional services. Among the latter, one out of three ends up using technical devices that help compensate for their hearing loss. As we all know, more hearing aids are kept in cupboards than in ears. Furthermore, the delay between the first signs of hearing difficulties and clinical consultation is estimated at about 10 years (Stephens, Barcham, Corcoran, & Parsons, 1976).

In other words, there are thousands of people, in particular, industrial workers and elderly people, who have developed a hearing loss that results in numerous difficulties in everyday life, but who cannot identify with a specific social group sharing the same condition. This is especially true for those who have never sought professional services. These people cannot identify with and fully participate in the hearing world, nor can they identify with or wish to belong to Deaf culture (Noble, 1978).

The audiological literature provides extensive descriptions of the physiological and functional status of impaired hearing, but much less of the consequences of impaired hearing in everyday life. At the *Groupe d'acoustique de l'Université de Montréal*, we have focussed our investigations on the latter dimension of the experience of hearing loss, particularly among industrial workers. We believed that, in order to understand their experience, questionnaires

were useful, but that we should also interview them about the consequences of hearing loss at work, at home, and in their leisure activities. We wanted to describe the perceptions of hearing difficulties in the words of those workers in order to grasp the very meaning of their experience of hearing impairment.

In such a study conducted with male workers, data collection involved two steps. First, a questionnaire survey was undertaken with a group of 250 participants from different plants (Hétu, Getty, Beaudry, & Philibert, 1994). It inquired about the knowledge the workers had of occupational hearing loss (OHL) and the attitudes and behaviours they reported adopting towards hearing-impaired co-workers. An inductive approach—the focus group interview—was used to complement the quantitative findings with four groups of eight to 10 workers (Hétu, Getty, & Waridel, 1994). The objectives of the focus groups were: (a) to understand how workers characterize a co-worker who has an impairment that involves no visible sign, (b) to identify the conditions that trigger social withdrawal and isolation behaviours, and conditions that make workers with OHL decide to seek help, and (c) to define the type and methods of help that such workers find might minimize social withdrawal and isolation. These interviews were tape recorded and the content of the discourse was analyzed with a phenomenological approach.

The above approach may seem obvious to anthropologists, but it is not obvious in a field such as audiology, which focuses on quantitative evidence. Analyzing what people say and how they talk regarding a problem is often considered unscientific or preliminary work. However, if the object of the study is the perception of individuals, the most straightforward and valid approach, in our view, is to question people directly.

### Attitudes and Behaviours Characterizing Workers with OHL

The findings from the focus group interviews converge in showing: (a) that the fear of stigma associated with the hearing loss governs the coping strategy, and (b) that the problem-solving process can take a long time and depends, in most cases, on the support of the spouse.

The following excerpts characterize workers' perceptions of the *feelings* of someone with OHL:

- "He must feel stressed and frustrated."
- "He must feel inferior, shy, because of his disability."
- "He must be afraid of being judged as not bright; of being joked at;

of being rejected or disliked.”

“He must feel lonely, isolated, closed off from everyone.”

“He must make a lot of effort.”

Perceptions of the *behaviours* adopted by workers with OHL were:

“He conceals his impairment.”

“He pretends, he tries to pass as normal.”

“He avoids applying for promotion.”

“He may drink a lot.”

“He may become angry and violent if someone jokes at him because of his impairment.”

The perceptions reported above are all negative; all clearly reveal the effects of stigmatization if one discloses one’s impairment. Disclosure leads to being put aside, being rejected, losing the sense of belonging, and being looked upon as abnormal; such responses exactly fit the definition of stigmatization proposed by Goffman (1968).

### Perception of Experience of Hearing Difficulties

Having a hearing impairment is seen as a condition that needs to be hidden. It leads to a negative self-image—seeing oneself as diminished, weak, less of a person. It is understandable that, with the threat of stigmatization surrounding an invisible impairment, one would do everything to conceal the impairment.

Following are statements made by workers describing their fear of disclosing their hearing difficulties:

“Being deaf is a degrading condition, a sign of being diminished, of being a weak person.”

“Being identified as deaf means being rejected by the others.”

“Showing signs of hearing loss invites others to make nasty jokes.”

“Hearing aids give the person a weird appearance.”

“Wearing a hearing aid opens up the possibility of being made fun of and of being looked at as old.”

“If the employer knows about the impairment, the worker could lose his job or be denied a promotion.”

“A worker affected by OHL will be less competent as a group leader, a supervisor, or a foreman.”

Any sign of impairment is seen as a weakness that provides an opportunity for others to make discrediting jokes. These perceptions are obviously not conducive to solving listening and communication problems resulting from hearing impairment. Within this context, hearing aids are very explicitly associated with the stigma of deafness. It

is therefore preferable to not understand what is being said than to wear a hearing aid that would reveal their hearing loss to all. The price of disclosure is too high to pay. It would mean serious damage to their image of themselves.

The participants in the focus groups all agreed with such perceptions; no participant expressed an opposite opinion about the experience of hearing loss in the workplace. Interestingly, each focus group gave some participants the opportunity to disclose their own hearing difficulties to co-workers, with whom they had worked for several years. But the participants emphasized the fact that this was due to the particular circumstances of this group interview, stating: “This is the first time we (have) talked about this.”

Sharing the above perceptions also gave the participants the opportunity to describe the passivity and withdrawal from any action that could solve their hearing difficulties. The solution again meant disclosure, which was unthinkable.

“Workers report that they know they have some degree of hearing loss but they do not take any step to overcome hearing difficulties.”

“Hearing loss is kept a secret even among older workers.”

“Workers deny having a hearing loss even if they repeatedly misunderstand what is being said.”

“Hearing impaired workers pass off as being of normal hearing;

They refrain from asking to have things repeated;

They assert ‘I am not deaf’ when they have misunderstood.”

These findings were highly consistent with those of previous studies we conducted using interviews with individuals, couples, and groups prior to and during the development of a rehabilitation program for workers with OHL and their spouses (Getty & Héту, 1991; Héту & Getty, 1991). The bulk of the data converge in showing that the stigma associated with hearing loss governs the method of coping with hearing difficulties, and that the spouse plays the most significance role in the problem-solving process.

### A Possible Culture of Workers with OHL

If the fear of being stigmatized as deaf is central to the experience of hearing loss in the workplace, and if the most powerful attack on self-esteem comes from disparaging expressions from co-workers, the resulting reluctance to disclose hearing loss means that workers with OHL have no culture of their own and no visible expression of their impairment. Efforts are made to cope and meet auditory demands without disclosing their loss of capacity. Every step is taken to “stay in the closet”. Hiding the effects of OHL implies that this condition is not known to others and that

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excessive noise in the workplace is not viewed as a problematic situation.

While there is no culture of workers with hearing impairment, there is male worker culture that can strongly modulate the way hearing loss is experienced. It would be interesting to study such interaction further. One could, for example, investigate the influence of gender on stigmatization attitudes in the workplace. Anthropological research in the workplace is obviously needed to better understand the intricacies of impairment perception among co-workers.

The influence of culturally-defined social roles on the way hearing impairment is experienced is further supported by the findings of a pilot investigation conducted with women with an acquired hearing loss (Waridel, Héту, & Getty, 1994). It shows that the experience of hard-of-hearing women differs from that of men in several respects. The words they used to describe the effects of hearing loss in their everyday lives are different: they articulately described how having a hearing loss reduced the pleasure they had in pursuing various activities. This was never heard from men with OHL. Women were also alone in expressing their dissatisfaction with not being able to play their social roles as nurturer and communicator in their intimate relationships. Furthermore, they felt they had very little, if any, support from their spouses, in contrast with most males with OHL. In order to extend our research on these dimensions of handicap associated with acquired hearing loss, we are presently studying the effects of gender and ethnicity on the experience of having an acquired hearing loss.

## Implications for Health Professionals

We as interveners have our own culture, which more or less strongly modulates our interventions. One basic dimension of this culture is the medical (curative) model of professional help: "We, as experts, know the clients' problems, but the clients don't; we have the solution to their problems." This framework tends to make professional interventions uniform across individuals and focused on short-term effects. Our diagnostic, rehabilitation, and evaluation tools are more or less the same regardless of who is in front of us, an individual, male or female, an elderly person, a person belonging to a different ethnic group, a couple, or a group.

Findings from the aforementioned studies led us to strongly believe that, in order for our services to be accessible and efficient, we must question our practice and take into consideration the diversity of the life conditions of the people we meet. For this purpose, we must learn from the people themselves by listening to how they talk about their

experience with health problems. Such knowledge is a prerequisite for making our services accessible and finding a way to reach everyone who needs such services.

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