# CONTRIBUTED PAPERS

# Emotional Responses Associated with Meniere's Disease

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The audiometric and symptomatic profiles of individuals with Meniere's disease are familiar to most audiologists. Professionals are less likely to be familiar with the emotional impact of the disease. The range of emotions is similar to that experienced by other individuals with hearing loss. However, adjustment is complicated by the unique combination of symptoms presented by the disorder. Emotional responses are summarized as well as the factors that contribute to the emotional state of Meniere's disease patients and their families. Suggestions for counseling and providing support are discussed.

Audiologists find Meniere's disease intriguing for its classic symptomology of a fluctuating hearing loss, vertigo and tinnitus. However, it is the episodic and often chronic nature of the disorder that distinguishes it from many other ear pathologies. Patients may experience frequent attacks over many months or can remain symptom free for years. Patients often report that the attacks are preceded by fullness in the ears, increased tinnitus, or other sensations that may provide them with a few minutes to prepare for the debilitating effects of vertigo.

The hearing loss associated with the disorder can be unilateral or bilateral, usually begins in the low frequencies, but can flatten out as the disease progresses (Kitahara, 1990). It has the potential to become quite severe. Individuals who undergo surgical intervention may lose all usable hearing in the affected ear. Additional complications may include severe recruitment and unsteadiness in between attacks of vertigo (Kitahara, 1990).

The dynamic nature of Meniere's disease results in an equally dynamic emotional response. Patients report a wide range of emotions that change in accor-

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dance with the attacks and the symptoms they experience. The fluctuations are confusing and contribute to patients' difficulty in coping with the disease process. Audiologists working with individuals with Meniere's disease should discuss these issues with their clients and their families as part of the rehabilitation process. The first step is helping them recognize the emotions that may occur in association with Meniere's disease and what situations are likely to trigger those responses.

## PATIENT EMOTIONAL RESPONSES

Patients with Meniere's disease report a range of emotional responses. For example, the emotions listed in Table 1 were identified by individuals and their fam-

Table 1 Emotions Commonly Associated with Meniere's Disease

Less severe level of emotion		Most severe level of emotion	
Grief/loss		Shock	
Avoidance		Denial	
Sadness		Depression	
Irritability		Anger	
Embarrassment		Shame	
Anxiety		Fear	
Uncertainty	Confusion	Helplessness	
Loneliness		Isolation	
Understanding		Acceptance	

ilies during a meeting with a Meniere's disease self-help group. Many of the emotions are consistent with those reported by individuals with other types of acquired hearing loss (Rothschild & Kampfe, 1997). Although they have been presented here in the order reminiscent of the grieving process described by Kubler-Ross (1969), the chronic nature of Meniere's disease often prevents permanent resolution. Patients move in and out of the various emotional states as the episodes occur. It is best not to view the responses as stages, but as states. Clinicians often erroneously assume that there is a specific order associated with the emotions accompanying loss of physical function. However, each patient reacts differently and may move through emotional states at different rates and times. They also may skip or return to different emotional states as their circumstances change. In fact, in an extensive review of data on patients recovering from spinal cord injury, one researcher concluded that there was a lack of reliable, valid evidence to support the validity of viewing recovering in terms of emotional stages (Trieschmann, 1988).

In addition to variations in emotion, there is a range of severity of emotional response. The severity may be associated with the frequency and intensity of individual episodes as well as the length of time the individual has had the disorder. For example, long-term sufferers may become more despondent with repeated disruptions of lifestyle and continued reduction in hearing level.

#### FACTORS CONTRIBUTING TO EMOTIONAL RESPONSES

### **Diagnosis**

Patients are often confused by the array of tests that are performed and anxious about the outcome. They may have been told the tests are being performed to rule out a space-occupying lesion or other neurological disorder. When test results are negative for neurological involvement the patient experiences a sense of relief. However, the relief is replaced by confusion, frustration, and concern when it is apparent there is not going to be an immediate resolution.

#### Reoccurrence

Constant low-level anxiety occurs when attacks reoccur over time. Patients have little time to prepare for episodes and therefore are hesitant to plan trips away from home. Long-term sufferers fear loss of their jobs and/or the economic hardships associated with reduced hours of work. Stress is often reported as a contributing factor in triggering attacks. Therefore, it is not uncommon for individuals to reduce hours of work or seek alternative employment in an attempt to reduce stress. The added burdens imposed by the changes in income can offset the benefits of a reduced workload. In addition, there is a loss of self-esteem associated with any limitations imposed on employment options.

# Fluctuating and Progressive Hearing Loss

The hearing loss associated with Meniere's disease may be quite mild in the initial stages and therefore seem a minor concern when compared with the consequences of vertigo. Well-meaning professionals may try to reassure the patient that the effects will be minimal when the loss is unilateral. As the hearing loss progresses and communication difficulties increase patients may feel misled by the lack of information they initially received.

# **Tinnitus**

Clinicians often underestimate the degree to which tinnitus interferes with communication and its potential as a trigger for strong emotions. For some patients, the degree of interference they report from tinnitus is greater than one might expect based on the intensity of a tone matched to the loudness of their tinnitus. They are often given little information on coping strategies (Vernon, 1998). It is hard for family members to understand what they cannot see or hear and thus, the patient feels isolated. Even when the hearing loss is stable and the patient is

otherwise symptom free, the tinnitus is a reminder of their condition. Because fluctuations in tinnitus may signal an attack of vertigo, changes in intensity have the potential to produce high levels of anxiety.

#### Recruitment

Individuals report that recruitment is a frustrating component of Meniere's disease. The patient's changing sensitivity to sound often results in irritability and a desire to avoid situations that may prove to be uncomfortable. The fluctuating hearing loss and recruitment associated with Meniere's disease make it difficult to fit hearing aids successfully. Patients may express frustration with the devices and difficulty adjusting to them if attacks are frequent. The advent of digital technology has made it possible to reprogram hearing aids taking into consideration both the change in hearing status and the increased sensitivity associated with recruitment. However, a patient may not feel physically able to travel for several days after an attack and by then hearing may have returned to pre-attack levels.

## Vertigo and Nausea

Unquestionably the most disturbing aspect of an attack of Meniere's disease is vertigo. The disorientation and loss of control result in helplessness and fear. Patients also report guilt when they must rely on others for assistance and shame when the vertigo is accompanied by nausea and vomiting. These emotions occur regardless of whether the individuals are with strangers or family members. The emotions tend to be more severe in the presence of strangers and thus patients tend to avoid being alone in new places.

# Family and Friends

Patients with Meniere's disease are concerned about being a burden to family and friends. They are saddened by the sense of loss they feel when they cannot participate in activities as spontaneously as they did before the onset of the disease. Expressions of concern and offers of assistance, while initially comforting, gradually become a reminder of reduced functioning and can contribute to their sense of inadequacy. Family members also feel a sense of loss and inadequacy as they realize there is little they can do to alleviate the distress of the individual with Meniere's disease. The emotional turmoil the individual family members experience can often be tied directly to the patient's sense of well-being (McRae & Smith, 1998).

# **COUNSELING STRATEGIES**

#### Identification

Counseling patients with Meniere's disease begins with honest evaluation of their situation and the degree of perceived disability they are experiencing. In addition to understanding the disease process itself, the clinician should gain an understanding of the individual's perceived strengths and weaknesses including those related to coping mechanisms. It is also important to understand the patient's physical and social environment, and a sense of the depth of emotional responses as an indicator of the need to refer for counseling (Belar & Deardorf, 1995). It may be that an analysis of the frequency and severity of emotions suggests that a referral to a psychologist is warranted. Frequent bouts of depression, high levels of anxiety, and isolation are indications that regular counseling should be considered. In addition, the individual's perception of his/her ability to cope with the disorder should be investigated. Persons are more likely to become depressed if they doubt their capacity to deal effectively with the situation (Devries & Gallagher-Thompson, 1994).

Developing sensitivity to cultural differences is also important. (McRae & Smith, 1998). Does the individual view illness and the role of the medical community differently from the health care providers from whom he/she is receiving services? If so, what is the potential impact on their reaction to the disorder and their interest in pursuing medical interventions and exploring coping strategies?

# **Problem Solving**

Discussing the disease process will help the patient to recognize the nature and variety of their emotional responses. They need to be advised that these responses are common and normal for individuals undergoing stressful situations of all kinds. Family members should be encouraged to participate in these discussions since the patient may not be aware of the extent to which they share similar feelings.

Diaries are helpful in identifying the frequency and severity of emotional responses. The process of documenting their experiences can be helpful for the patient, family members, and the clinician. Written documentation will undoubtedly help to initiate discussions about the situations triggering the emotions, frustrations with the reactions of others, and the difficulties experienced with amplification systems in the presence of fluctuating loss and recruitment. Participation in support groups can serve the same purpose. The realization that others are experiencing similar problems is often reassuring. The process of problem solving within the group can be empowering (Luterman, 2001).

Encourage patients to take whatever actions will help them feel more comfortable with the consequences of the disorder. Examine their lifestyle to determine how it can be modified. For example, make sure they have a plan for dealing with attacks and knowing who in the family is best equipped to be of service in different situations (Power, Orto, & Gibbons, 1988). Often families do not have a set method for dealing with a crisis that accommodates the strengths and abilities of individuals. Crisis denotes change and habitual roles may need to be flexible to deal more effectively and efficiently with new situations (Bass, 1996). It might also be possible to increase the number of persons that are willing to be of assis-

tance. Perhaps having a cell phone and a specific contact person or persons within the vicinity of a trip would help the patient feel more comfortable with venturing out of the house and into new situations. Sometimes it is the anxiety and not the disease itself that is the most debilitating aspect of a disease process.

#### CONCLUSIONS

Many of the concepts presented here are familiar to clinicians. However, it is easy in the confines of a busy clinical setting to overlook the emotional needs of patients experiencing chronic illness. One may assume they are getting the information they need from physicians and that the emotional support they require is forthcoming from friends and family members. Unfortunately, this is often not the case with patients with Meniere's disease. A greater sensitivity to their needs and open discussions of emotional consequences with patients and families can provide a more successful rehabilitative experience.

#### REFERENCES

Bass, D. (1996). Family support across programs and populations. In G. Singer, L. Powers, & A. Olson (Eds.), Redefining family support (pp. 39-55). Baltimore: Paul J. Brooks Publishing.

Belar, C.D., & Deardorf, W. (1995). Clinical health psychology in medical settings: A practitioner's guidebook. Washington, DC: American Psychological Association.

Devries, J., & Gallagher-Thompson, D. (1994). Older adults. In F. Dattilio & A. Freeman (Eds.), Cognitive behavioral strategies in crisis intervention (pp. 200-218). New York: Guilford Press.

Kitahara, M. (1990). Concepts and diagnostic criteria of Meniere's disease. In M. Kitahara (Ed.), Meniere's disease (pp. 1-12). Tokyo: Springer-Verlag.

Kubler-Ross, E. (1969). On death and dying. New York: Macmillan.

Luterman, D. (2001). Counseling persons with communication disorders and their families (4th ed.). Austin, TX: Pro-ed.

McRae, C., & Smith, C. (1998). Chronic illness: Promoting the adjustment process. In S.S. Roth-Roemer, S. Kurpius, & C. Carmin (Eds.), The emerging role of counseling psychology in health care (pp. 137-156). New York: W.W. Norton.

Power, P., Orto, A., & Gibbons, M. (1988). Family interventions throughout chronic illness and disability. New York: Springer-Verlag.

Rothschild, M., & Kampfe, C. (1997). Issues associated with late onset deafness. Journal of the American Deafness and Rehabilitation Association, 31, 1-16.

Trieschmann, R.B. (1988). Spinal cord injuries: Psychological, social, and vocational rehabilitation (2nd ed.). New York: Demos.

Vernon, J. (1998). Tinnitus: Treatment and relief. Boston: Allyn and Bacon.