

Factors to Consider When Providing Audiological Services to People Who Have Hearing Loss and Their Communication Partners

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ABSTRACT

Hearing loss has a variety of psychosocial effects that often negatively affect those who have it and their communication partners. The negative effects are seen in peoples' attitudes toward hearing loss, compliance with treatment recommendations, and willingness to change communication behavior. One result is the tendency to blame the hearing aids for problems in understanding what others are saying when other factors are the real contributors to communication breakdowns. Educating patients and their communication partners about these hearing loss-related factors that interfere with getting the maximum benefits from hearing technology is a necessary step in effectively managing hearing loss.

KEYWORDS: Human dynamics, psychosocial challenges, Ida Institute tools

Learning Outcomes: As a result of this activity, the participant will be able to (1) list the major categories of psychosocial challenges reported by patients and their communication partners; (2) select appropriate Ida tools to use to assess the level of their patients' psychosocial challenges.

I received my first hearing aid (a body aid) in 1953 at the Walter Reed Army Hospital in Washington, DC. Thirty-one years later, I began to work with people who had hearing loss at the then Self-Help for Hard of Hearing, now Hearing Loss Association of America

central office in Bethesda, Maryland. We formed a group of 10 people to work on coping strategies for dealing with the stresses related to hearing loss. That group met weekly for 32 weeks. Another group also began in Baltimore, which continued on a weekly basis for ~22

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weeks. It was through working with these wonderful people that I began to learn about the effects of my own hearing loss as well as about the experience of other people—those with hearing loss and those who were their communication partners. I then took what we had learned around the United States (48 of the 50 states) and in several locations in Canada. What I discovered is that, independent of location or nationality, the experience of people with hearing loss and their communication partners is basically similar (i.e., people for the most part report similar experiences, problems, and dilemmas).

What became evident very early is that there are issues related to hearing loss that produce problems in communication and relationships that are often not addressed by professionals who serve people with hearing loss and their partners. One result is that people frequently blame the hearing loss for the problems they experience, when, in fact, it is not the hearing loss itself but something related to the hearing loss that is at the root of the problem. Fortunately, most of these other causes of communication breakdowns are correctable. Unfortunately, most people are not aware of these other causes, and when communication problems inevitably arise, many blame their hearing aids for being improperly adjusted or their service providers for being ineffective. I believe it is to everyone's benefit to inform patients and their communication partners about these other factors that influence patient's understanding, attitudes, adjustment, and adherence/compliance related to hearing loss.

This article addresses several of the major contributing factors reported by many people affected by hearing loss that influence the effectiveness of hearing aids and other services provided by audiologists. The following is a quote from Lise Lotte Bundesen, the Executive Director of the Ida Institute: "The Institute seeks to foster a better understanding of the human dynamics of hearing loss. By serving as a catalyst for knowledge sharing and the development of innovative and practical tools, the Institute assists hearing care professionals in helping hearing impaired people address the physical, psychological and social challenges of

hearing loss." What follows are several examples of challenges related to hearing loss that might not be taken into consideration by many audiologists, but which have implications for patients' adjustment to hearing loss and for their adherence/compliance with treatment recommendations.

PHYSICAL CHALLENGES

At the physical level, many people who have hearing loss report being chronically fatigued.¹ The sustained visual and auditory attention required in communication situations can result in exhaustion. Some people report being so exhausted by the end of the week that they need to sleep the entire weekend to have enough energy to return to work on Monday. That routine is not contributing to a happy or healthful style of life. Another contributor to fatigue is chronic high levels of emotional distress resulting from anticipating or experiencing communication and other problems associated with hearing loss. The major issue with fatigue is that, when tired, it is difficult to sustain the level of attention necessary for understanding what people are saying, and communication problems are frequently the result. If the patient is unaware of the effects of fatigue on attention, he or she may resort to blaming the technology as being inadequate or the provider as being incompetent. It can be helpful to provide patients with information about the relationship between hearing loss and fatigue and to provide information about ways to combat fatigue and methods of improving the skill of paying attention. This is an inexpensive way of helping people get the most benefit from their assistive listening technology.

Using Ida Institute's line tool (see Clark, this issue)² can be useful in determining if fatigue is a relevant factor for patients. Some questions to ask using the line tool might be, "How much energy do you have during a typical day at work (or home)?" "How difficult is it for you to understand what other people are saying to you?" "How difficult is it for you to do what is necessary to better understand what other people are saying to you?" Then use the box tool (again see Clark, this issue)² to

determine the specific costs, benefits, and barriers to making the necessary changes. If it is determined that fatigue is a significant factor for the patient, recommendations regarding what to do to be less tired are in order. Discussion of sleep patterns, exercise, and diet can uncover the need for changes in these areas. Then the box can be used to determine the costs and benefits of making changes in these areas and to suggest ways of decreasing the costs, increasing the benefits, or both.

PSYCHOLOGICAL CHALLENGES—EMOTIONAL

At the psychological level, we often see people who suffer from frequent high levels of negative emotional arousal, such as anxiety/fear or irritation/anger.³ There are several unfortunate consequences of high emotional arousal if it is experienced frequently, is prolonged, or occurs at high intensity. First, negative emotions result in hormonal imbalances that are often damaging to physical and psychological health.^{4,5} Second, intense or frequent high emotional arousal often results in physical and emotional depletion, leading to apathy, inertia, and depression. Low arousal can then, as stated previously, negatively affect the ability to sustain attention and be proactive in preventing or reducing communication breakdowns. Third, when emotional arousal is high, it interferes with cognitive functioning, resulting in problems with judgment, decision making, and problem solving. When that happens, the person experiencing these emotional reactions to communication problems is often unable to think clearly to determine the cause of the communication breakdown and consequently is unable to provide a solution for it.

Fourth, negative emotions, such as anger and anxiety, are often detrimental to establishing or maintaining good relationships with other people, who usually do not appreciate being the target of irritation or anger and often find it difficult to be around someone who is chronically anxious. Typical reactions by other people include finding excuses to get away from the offending individual and finding ways to avoid her or him in the future. Unfortunately, some people who have hearing loss are unaware

of the effects of their anger or anxiety on others, and, too often, we see people who make the mistake of blaming their hearing loss for any and all relationship problems. It is important for such people to learn that it is their way of handling the difficulties related to hearing loss rather than the hearing loss itself that is producing their social problems. It is helpful for them to see that negative emotional arousal can contribute to communication difficulties, and communication difficulties can contribute to negative emotions, resulting in a cycle that is self-perpetuating and unhealthy. Helping patients understand this relationship and helping them learn to manage negative emotional arousal is another good way to help them get the most benefit from their assistive listening technology. It is an optimistic perspective because most emotionally induced problematic reactions and behaviors can be changed, even though the hearing loss is permanent.

Using the line and box tools can be an effective way to assess the level and type of emotional arousal that the individual experiences, especially in difficult communication situations. Using the line tool, some questions might be, “How emotionally upsetting are communication difficulties for you?” Or, alternatively, “How relaxed are you when communication becomes difficult?” Using the box tool, one might then ask about the costs and benefits of becoming angry or anxious. What are the possible costs and benefits of being more relaxed in difficult communication situations?

PSYCHOLOGICAL CHALLENGES—COGNITIVE

At the cognitive level, many of the people we have seen did not have adequate *information* about what to do to prevent or reduce their hearing loss-related communication problems. They were unaware of the many different causes of communication breakdowns and tended to blame their hearing loss for all of those kinds of problems. If a person is unable to determine the cause of a particular communication problem, she or he will also be unable to determine the solution for that problem and will often become confused and feel helpless.

We have identified at least 42 different causes of communication breakdowns, only two of which are the hearing loss itself—the type and decibel level. The other causes of communication difficulties fall into three categories: speaker factors, listener factors, and environmental factors. Examples of *speaker factors* include failure to get the person's attention before speaking or talking too rapidly. Examples of *listener factors* are inability to pay attention or failure to inform the speaker about what to do to be understood. *Environmental factors* are background noise or distance from the source of the sound.

Once patients are aware of the variety of causes of communication problems, they are able to identify the source of a problem they are experiencing and then offer a solution, such as, "I need to see your face when you are talking to me" or "We need to move to another location to continue this conversation." It is also helpful if people learn to preface their requests with, "Because of my hearing loss. . . ." This is because asking someone to make changes in their communication behavior or to change some feature of the environment may not result in cooperation unless the person speaking has a good reason for making such a change. Again, people need to learn the importance of adopting these proactive communication tactics and also learn how to do so effectively. This information is not intuitively evident; it requires education and training.

A second cognitive challenge that is sometimes necessary is providing people with *permission* to do what needs to be done to prevent or reduce hearing loss-related communication problems. For example, one woman in a group I conducted complained of inability to understand what was being said at a dinner party the night before. She said that the table had a large flower arrangement that obstructed her view of the people seated opposite to her and that the stereo blared music the entire evening. I asked if she had requested the hostess to remove the obstructions and she responded, "Oh, I couldn't do that; it would have been impolite." We discussed the issue of which is more impolite, making such a request or pretending to understand and/or asking for frequent repetition of what had been said. She agreed that

bluffing and needing frequent repetition are less conducive to establishing and maintaining good relationships than is requesting speaker or environmental modification that will result in better understanding of what is being said.

Using Ida Institute's Dilemma Game cards (described at <http://www.idainstitute.com>) can provide valuable information about people's reactions to communication situations and what they are currently able to do in terms of requesting changes. Presenting simple scenarios similar to the dinner party mentioned above and asking patients what they would do in such situations provides valuable information about what they know to do and about their view of the acceptability of doing it. The line can provide an indication of how important it is to them to understand what is said in such situations and also how willing they are to do what is required to be able to better understand. If they need permission to do what is necessary to better understand, using the box can be most valuable in helping them see the costs and benefits of maintaining the status quo (misunderstanding, remaining silent, bluffing, requesting frequent repeats, etc.) and of making the suggested change (informing/reminding the other people about the hearing loss and suggesting ways of facilitating communication).

Something else that also needs consideration in terms of cognitive abilities is the interaction between emotional arousal and cognitive processing. Data⁶ show that when arousal is high, cognitive processing abilities decline. High emotional arousal has particular impact on the language processing centers in the brain. The effect is a reduced ability to retrieve and use information that is stored in memory. For example, if a patient has a history of high emotional arousal in difficult communication situations, that establishes a baseline or default level of arousal in those situations. The person may have recently been given information about what to do in difficult communication situations, have had some opportunity to practice doing it, but be unable to retrieve it when needed in a critical situation. We tend to revert back to habitual, default, or baseline reactions when similar, precipitating situations arise. Frequent practice over time

resets the emotional arousal to a lower baseline level, reducing interference with cognitive processing. Then, newly learned and more effective reactions can replace the old dysfunctional ones when difficult situations arise. In general, the longer the default level has been in place, the more difficult it can be to change the baseline, requiring more practice of the newly learned reactions/behaviors.

Using Ida Institute's Patient Journey tool (see Gregory, this issue)⁷ as a starting point can provide insight into how firmly established identified ineffective communication habits may have been in place and provide an estimate of how long it may take to reset their baseline level. For example, someone who has a recent precipitous loss of hearing after a lifetime of normal hearing probably has not had time to firmly establish bluffing as a habit. Someone who has had progressive hearing loss for 30 years may well have firmly established bluffing as a habit and may require more time and practice to extinguish that habit and establish a more functional communication alternative in its place. Questions using the line can indicate how important and motivated the person is to change the baseline level and how confident he or she is that it can be done. Low motivation and/or confidence can be addressed using the box to determine the person's perception of the costs, benefits, and barriers related to maintaining the status quo or making changes.

PSYCHOLOGICAL CHALLENGES— BEHAVIORAL

Knowing what to do and being able to *do it effectively* are each important for learning to manage communication situations. *Effectively* is the key term. As stated, practice is required in order for people to learn new behaviors, establish them as habits that feel comfortable, and use them effectively. Practicing new behavior also requires feedback about how well it has been performed. For example, I may *know* that I need to ask you to raise your voice to the level at which I can hear it, but do so in a way that turns you off. If I say (or imply by tone of voice or body language), "Speak up, stupid; how many times have I told you that I have a hearing loss?" I have informed you about

what is required, but the way I did it most likely was not conducive to generating your cooperation. Granted that not many people are that insensitive, but many really do not feel comfortable informing others about the fact of their hearing loss, and do not know how to do it in a way that is comfortable. It can be even more difficult for a person to inform others about what they need to do differently to be understood. These are seemingly simple behaviors that need instruction and practice with gentle feedback until they become comfortable and habitual.

Bluffing, as mentioned previously, is a frequently observed behavioral habit among those who have hearing loss that is often difficult to modify. Bluffing has detrimental effects on relationships and on the bluffer's self-esteem, causing problems both socially and personally. Socially, when the person talking finds out that the listener has been pretending to understand when in fact she had not, that is often interpreted to indicate that as the listener lacks interest in what is being said, resulting in the speaker's desire to terminate the conversation. Personally, bluffing means pretending to understand when the person, in fact, knows that he or she does not understand what someone is saying. So, essentially, bluffing is a cop-out; it is a form of lying, and the people who do it know that they are not being honest and that they are fearful of acknowledging that they do not understand, and/or that they do not know what else to do to rectify the situation. This kind of deception is not conducive to feeling good about oneself and may be a source of depression and low self-esteem observed among some people who have hearing loss. In addition, bluffing results in missing information that may be important for the bluffer to know. For example, it is important to know what someone is saying in work situations, at the physician's office, and during intimate conversations.

Using the Ida Dilemma Game cards is a way of ascertaining if a patient relies on bluffing as a coping mechanism in communication situations. The box is an excellent tool for helping patients realize the costs of bluffing and the benefits of adopting more effective communication behaviors.

Other examples of behavioral challenges associated with hearing loss are the habits of escaping from or avoiding entering into social situations that have produced or might possibly produce communication problems.

SOCIAL CHALLENGES

At the social level, hearing loss affects everyone in the communication situation (i.e., communication partners as well as those who have hearing loss). If the person who is listening fails to understand what is being said, he or she has a problem. But, so does the person who is speaking and attempting to be understood. The Ida Institute recommends including communication partners in assessment and treatment. There are several reasons for doing so. First, including communication partners is important because family members, friends, and coworkers can foster or inhibit a person's adjustment to her or his hearing loss. Communication partners also can be a positive or negative factor in influencing adherence to treatment recommendations. Second, the communication partner may be more aware of or more willing to discuss problems and concerns that elude or embarrass the person who has the hearing loss. Third, both the person who is speaking and the person who is listening may each contribute to communication breakdowns, and the cooperation of both is usually necessary for preventing or reducing those breakdowns. It is therefore helpful when both participate in the assessment and when both are equally informed about available treatment strategies. Rather than perceiving hearing loss as "your" problem or "my" problem, we find it helpful if the people involved can view it as "our" problem and approach dealing with it from that perspective.

A major social challenge facing people who have hearing loss is staying connected to their social world, which, at a more intimate level, includes family, friends, and sometimes coworkers. The social world also includes, at a less intimate but still important level, distant family members, acquaintances, service providers, and shopkeepers. The issue is that when communication breaks down, there is often a mild to severe rupture in the relationship with conse-

quent emotional reactions in both the speaker and listener. Sometimes the relationship deteriorates to the point that the patient is actively rejected and pushed aside or passively ostracized by being ignored, left out, or discounted. Research indicates that such loss of attachment to other people often results in *social pain*.⁸ This reaction to loss of attachment to other people appears to be an evolutionary development that contributes to the survival of human beings (and of other mammals as well). Humans are dependent for many years on other people for their survival, and social attachment is a basic, prewired, survival need. Neurological research shows that the neural pathways in the brain that mediate social pain are the same as those that mediate physical pain. It is also a fact that a person's sensitivity level to social pain matches his or her sensitivity level to physical pain—the correlation is very high. Both forms of pain most likely evolved from the same basic survival need—to alert us to threat or danger. The danger of loss of attachment to significant others for a human infant is obvious, but, thinking in terms of prehistoric times, the threat of separation from one's social group most likely had survival implications even for adults. The concept of social pain resulting from separation from others or loss of attachment has many implications for people who have hearing loss and their communication partners.

When social pain is experienced either by traumatic rejection (e.g., a divorce or loss of a job) or by less traumatic but frequent rejection, the defense mechanisms often used to reduce the pain are escape and/or avoidance. The person experiencing social pain finds ways to leave situations in which the pain is experienced and attempts to avoid those situations in the future. Unfortunately, these tactics produce other unwanted effects such as loneliness, shame, and boredom. From a treatment perspective, escape or avoidance behaviors prevent the person from using effective communication behaviors, such as informing others about his or her hearing loss, informing others about what they need to do differently to be understood, and using helpful assistive listening technology. There are many implications of social pain for audiologists and the population they serve. For

example, having newer and more expensive hearing aids may well increase one's ability to hear, but of what use are they conversationally if the person regularly isolates him- or herself?

Using Ida Institute's Communication Rings (see Montano and AlMakadma, this issue)⁹ can be very helpful in getting a clear picture of the level of social connectedness of patients. How many people does the patient include in the inner two circles? How does the patient respond to the questions being asked when using this tool? Does the person evidence loneliness, sadness, despair? The line can be used to determine how important social connections are to both the patient and the patient's communication partner. The line also can be used to determine how willing both may be to do what is required to establish or reestablish social connections. It is useful to use the line to determine how confident each of them is in their ability to do what is required in this regard. When low levels of importance, motivation, or self-efficacy are revealed, it is helpful to use the box to determine the costs, benefits, and perceived barriers related to maintaining the status quo and to making desirable changes. Helping them both reduce the costs and/or increase the benefits of making the changes can improve their attitude toward hearing loss and induce more functional coping strategies.

However, if there is evidence of psychological or physical damage resulting from high levels of emotional arousal stemming from social pain experiences, it is likely that referral to mental and/or physical health providers may be indicated. For example, some people who have hearing loss develop posttraumatic stress disorder, which requires specialized mental health treatment. Post-traumatic stress disorder can result from either a high-intensity traumatic experience or from low-intensity but frequent negative experiences, and people who have hearing loss are at risk for having those kinds of experiences.

At a different social level, there are also cultural issues that can affect a person's ability to adjust positively to hearing loss. The negative social stigma that exists in many countries of the world can be a major factor in whether or

not people will reveal the fact of their hearing loss to others.¹⁰ If a person believes that he or she will be seen by others as being less acceptable, less competent, or less desirable because of hearing loss, that belief can increase the likelihood that he or she will attempt to hide the fact of the hearing loss.¹¹ In that case, the efforts involved in attempting to hide the hearing loss coupled with the fear of being found out are likely to increase anxiety and add to the person's tendency to avoid social situations.

Asking questions about how they view hearing loss when using Ida Institute's Personal Journey and Communication Rings can shed light on the degree to which patients and communication partners buy into the negative stigma and hold attitudes about hearing loss that foster hiding it, and therefore interfere with adaptively accommodating to it. Questions regarding the attitudes about hearing loss held by people close to the patient such as family members, friends, and coworkers can reveal the presence of stigmatizing factors held by people close to them who may have some influence. Questions about the patient's views about others who have hearing loss can reveal his or her tendency to self-stigmatize, prompting the audiologist to inquire further about the patient's attitudes about his or her own hearing loss. One might use the Communication Rings to get this information about negative stigma among the person's closer family and associates. For each person designated in the inner circles, a minus sign could indicate a negative view, a plus sign could indicate a positive view, and a zero sign a neutral attitude. If the evidence indicates that the patient or the communication partner or both have attitudes toward hearing loss that have been affected by stigma, one can use the line to determine the degree of negative attitude. Then the box can be used to determine the probable costs and benefits of adopting negative versus positive attitudes.

TWO WAYS OF DEALING WITH THESE AND OTHER CHALLENGES

One of the best ways of preventing or reducing the psychosocial challenges frequently reported

by people who have hearing loss and their communication partners is by *teaching them ways to effectively manage communication situations*. When people learn to anticipate possible problems before they enter situations, they are in a position to take action to prevent or reduce those problems once they are in those situations. Knowing the typical causes of communication difficulties when eating in restaurants, for example, allows one to plan ahead to prevent the occurrence of those problems. One can inform the waiter that the person has a hearing loss, ask for a list of the specials to read, use assistive listening devices, have fresh batteries for the device and hearing aids, sit away from the door to the kitchen, avoid a place that has live music, and so on. There are at least 30 different things that one can do to prevent or reduce communication problems when dining out in restaurants.^{3,12-16} Many of these solutions carry over to other situations, such as business meetings, family dinners at holidays, and education/training classes.

For example, when communication problems still arise despite one's best prevention efforts, which they often do, we want the person who has hearing loss to be able to identify the cause of the problem and offer a solution to it. Even if that does not completely resolve the problem (e.g., the other person does not cooperate or the environment cannot be modified), the person with hearing loss can still feel good for having done the best he or she could in the situation. It also can be very helpful if he or she has learned how to manage his or her reactions in stressful situations.

The second way of helping people who have hearing loss and their communication partners effectively deal with difficult situations is by teaching them how to *manage their level of emotional arousal*. There are a variety of programs available that are focused on teaching people how to remain calmer in difficult situations. Yoga, meditation, progressive relaxation, deep breathing exercises, and so on have the goal of reducing emotionally charged reactions when under duress. The program that I prefer is Heartmath,⁶ which focuses on methods for

helping people quickly change their heart rhythms when distressed, allowing for decreased physiological arousal and increased cognitive clarity. All of these procedures require some instruction and practice over time, but the benefits of increased ability to self-regulate emotional arousal are well worth the effort required.

THE BENEFITS OF USING A GROUP FORMAT

An efficient and effective way to gather the necessary information from patients and their communication partners and to provide the education/training outlined in this article is by having people participate in a group. The primary goal of the group is focused on ways to better manage communication situations and better manage emotional arousal. The group format is an effective venue for:

1. Identifying the problems and concerns of people who have hearing loss and their communication partners.
2. Providing alternative solutions to the reported hearing loss-related problems.
3. Providing opportunity for people to practice new communication skills in a safe, non-threatening environment.
4. Providing feedback about their newly acquired efforts.
5. Providing opportunity to practice emotion-regulation procedures.

In a group setting, patients and their communication partners have opportunity to openly share their experiences related to the hearing loss. They also learn about the experiences of other people who are in similar situations, allowing them to see that many of the problems they experience are due to the hearing loss and not to some imagined personal inadequacy (i.e., the problems are similar among many other people in similar situations).

Information that is useful for the audiologist surfaces very quickly in such group settings. People often open up and share experiences with peers more rapidly than

they might in one-on-one situations with service providers. Another benefit to audiologists is that people learn to focus attention on communication behavior and environmental causes of problems rather than on their hearing aids. One audiologist who added group sessions in her practice reported a drop in return rate from 20 to 4%.

The use of Ida Institute's tools in group situations can accelerate the identification of problem issues, help people pinpoint communication objectives, identify barriers to progress, and generate problem solutions. Using the tools provides group members with a common frame of reference that facilitates mutual understanding, fosters positive attitudes, and encourages problem-solving efforts.

The Ida Institute is currently involved in generating and disseminating information about the benefits of conducting groups for audiologists, for their patients, and for their communication partners. Several of the authors of this journal issue have had considerable experience in conducting groups and are part of the Ida effort to increase the use of groups in audiology. If the reader has questions regarding conducting groups, contact the author of this article and he will see that you receive answers to them.

There are two additional options for providing the kinds of information presented in this chapter to patients and their communication partners. One option is using graduates of the Hearing Loss Association of America (HLAA) training program to work with people individually or in a group. The second option is recommending that they attend local HLAA chapter meetings where these issues are often discussed. The telephone number for the HLAA national office is (301) 657-2248.

NOTES

Name of Website: <http://www.trychin.com>.

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