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# Understanding the Stigma of Hearing Loss and How It Affects the Patient and Treatment Process

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Over 360 million people across the globe have a disabling hearing loss (World Health Organization, 2015) with about 35 million of those in the United States alone. Less than 25% of those who need hearing aids actually get them, though (American Speech-Language-Hearing Association, n.d). This could be because in most countries, there is a stigma associated with hearing loss. This stigma can make admitting there is a problem, seeking help, and accepting treatment a much more difficult process. It is imperative for an audiologist to understand this stigma and how the patient is being affected by it to best be able to offer effective treatment.

### Stigma

Stigma is a word that originates from the ancient Greeks, who used it to describe signs cut or burned into the bodies of criminals, slaves, or traitors. The signs revealed something bad about the moral status of the person (Goffman, 1963). The meaning of stigma has evolved since then, but the general idea is the same; individuals are no longer physically marked, but they are labeled by society. The definition of stigma is constantly changing due to changing times and opinions. Goffman (1963) described a stigmatized person as “a tainted, discounted” person who is different from the “normals.” Years later, Heatherton, Kleck, Hebl and Hull (2000) described stigma as, “a social construction that involves at least two fundamental components: (1) the recognition of difference based on some distinguishing characteristic, or ‘mark’; and (2) a consequent devaluation of the person” (p. 3). The definitions are similar in the sense that they both cause the stigmatized person’s value to decrease.

Stigma can be associated with physical differences, actions, mental capabilities, diseases, disabilities, race, gender, and many other personal characteristics. Stigma oftentimes exacerbates

an already difficult situation, including living with a disability. Stigma can be studied from the vantage point of the outsider or the insider (Gagne, Southall, & Jennings, 2011). Stigma most often is imposed upon others by those without the stigmatizing trait. Usually the trait that is being stigmatized deviates from what is considered normal in each culture. Self-stigma also exists, in which the person with the stigmatizing trait, knowingly or not, has the same views about the trait as the outsiders. This particularly can be threatening to one's identity (Gagne et al., 2011). Self-stigma can be even more detrimental to the person with the stigmatizing trait because it makes getting rid of the stigma much harder. Gagne et al. (2011) indicate that persons with impaired hearing, and who feel stigmatized, often develop maladaptive behaviors such as denying existence of hearing loss or avoiding situations where there could be a communication breakdown.

### Hearing Loss

Hearing loss can be defined as an inability or difficulty to hear auditory input. It can occur from aging, disease, genetics, or environmental factors (Sebastian, Varghese & Gowri, 2015). Hearing loss is considered a concealable trait since it is not easily recognizable with the naked eye. Concealable traits are just as, or possibly more, taxing on the individual than non-concealable. A great deal of effort may be exerted to keep the trait from being known. Some individuals may even deny that they have a problem since it is invisible. "Studies have also shown that concealing a stigmatizing trait increases the cognitive load required to take part in social interactions" (Gagné et al., 2009, p. 204). In this context, cognitive load refers to the added mental effort that is required when trying to hide a hearing loss and have a normal interaction at the same time. This increased cognitive load can lead to further psychological effects, such as depression, anger, self-esteem issues and more.

There are a number of psychological effects of both hearing loss and the stigma that is associated with it. Rezen and Hausman (1985) have discussed the psychological effects of hearing loss in depth. Their review of available evidence indicates that most people who have an acquired hearing loss are not sufficiently prepared to deal with the emotional stress and frustrations that go along with it. The psychological effects of any type of loss, hearing loss included, typically come in stages. The stages are denial, projection, anger, depression, and acceptance, which bear a strong resemblance to the five stages of grief (denial, anger, bargaining, depression, and acceptance) introduced by Kubler- Ross (1969). It is common for persons with hearing loss to begin the process by denying the existence of a problem. In fact, they may only realize it when it is called to their attention by someone else (Suss, 1993). Next, instead of experiencing anger, as described in the Kubler-Ross Model, Rezen and Hausman contend there is a projection stage prior to anger. During this projection stage, it is common for those with hearing loss to try to place blame on someone else. This is usually done by accusing the conversation partner of mumbling or not speaking loudly enough. The individual will then likely go through stages of anger and depression until finally acceptance can be reached. Only at this stage can treatment of a hearing loss be effective. The timeline for this varies for each individual but is typically a couple of months.

The extent of the impact of hearing loss on life varies greatly between individuals. One of the main determining factors is the age of onset. One study, led by Sebastian (2015), compared the impact of hearing loss on adults who had congenital hearing loss with those with acquired hearing loss. The study consisted of two groups. The first group was comprised of ten adults who had severe to profound bilateral hearing loss that was diagnosed before the age of three. The second group included ten adults with adult onset auditory neuropathy. Each participant was

required to fill out a Quality of Life questionnaire which tested in 16 domains, such as independence, socializing, health, personal expression, and different relationships. The results of the study showed that dealing with hearing loss as an adult led to more psychological stress than living with it from childhood. The main reason for this is because once a lifestyle has been established, it is hard to have such a dramatic change like a sensory deprivation. “Adults with early onset hearing loss would have grown up accepting the hearing loss whereas an adult who loses his hearing later in his life has already developed a personality and lifestyle, which does not assimilate the hearing loss” (p. 30) Another factor is how much people use their hearing and communication skills in everyday life. For example, a computer engineer, who spends most of his time alone working on computers, would be impacted less by hearing loss than a car salesman who relies on communication heavily throughout the day.

#### The Hearing Aid Effect

Much of the stigma behind hearing loss is related to the stigma of having a hearing aid, not necessarily the hearing loss itself. This has been called the hearing aid effect. “The hearing aid effect is the term used to describe the assignment of negative attributes to individuals using hearing aids” (Rauterkus & Palmer, 2013, p. 894). The term was first coined in 1977 when Blood, Blood, and Danhauer conducted a study to investigate how people were viewed if they were wearing hearing aids. The study involved showing two groups of 25 college students pictures of 12 white teenage males. Half of the teens wore hearing aids in the pictures shown to the first group; but did not wear hearing aids in the pictures shown to the second group. This was done to prevent bias based on their looks. The college students were then asked to rate the teen’s intelligence, achievement, personality, and appearance. For almost each attribute, teenagers wearing a hearing aid were rated significantly lower than when they were not. This study helped

to prove that there was a negative stigma toward those with hearing aids. Since 1977, there have been 15 similar studies investigating the hearing aid effect (Rauterkus & Palmer, 2013).

Almost 40 years later, the hearing aid effect still exists, but one study found that it may be declining. This could be due in part to the public being seen with electronics in their ears more often. The popularity of Bluetooth receivers, earbuds and earphones has made ear devices more commonplace. Rauterkus and Palmer (2013) conducted a study to determine whether the hearing aid effect truly is diminishing. This study involved five young men aged 15-17 who were photographed with five different devices: (1) a standard behind-the-ear (BTE) hearing aid with a standard ear mold, (2) a mini-BTE hearing aid with a slim tube open-fit configuration, (3) a completely-in-the-canal (CIC) hearing aid, (4) an earbud, and (5) a Bluetooth receiver. The photographs were then rated by 24 participants on eight attributes: attractiveness, age, successfulness, work ethic, trustworthiness, intelligence, friendliness, and education level. The results revealed that there was no significant stigma associated with hearing aids in this particular study. (Rauterkus & Palmer, 2013).

Although the results of the previous study indicated that the hearing aid effect may be diminishing, it is important to note that this is only from the perspective of the outsiders. The study does not take into account the feelings of those who actually have the hearing loss and are seeking hearing assistive devices. Johnson and Danhauer (2015), in a letter to the editor, explain that the Rauterkus & Palmer (2013) study only included teenage boys and college students, neither of which would be a group that typically includes hearing aid users. Those groups would, however, be more accustomed to seeing people with communication/entertainment devices in their ears. This could have skewed the results of the study. Also, the study lacked a control group. There were no photographs of a teenager with nothing in his ear, so it would be

impossible to determine that the hearing aid effect is diminishing since there was nothing to compare it to.

Blood, Blood, and Danhauer (1978) also conducted a study that investigated outsiders' perceptions of those with hearing loss, but executed it quite differently. For this study, 12 speech samples were collected from Caucasian, elementary school-aged males who were divided into 3 even groups: normal hearing, hard of hearing, and deaf. The study also used two photographs of each of the participants, one with a hearing aid and one without. Listeners heard all 12 speakers accompanied by a photo. The photos were then randomly assigned to speakers, which were different for each group. The listeners then rated each speaker on personality, intelligence, achievement, and appearance. The results revealed that scores increased toward "less-desirable" as the hearing loss increased. Also responses were more negative when the photos depicted the speaker wearing a hearing aid. This shows that children are discriminated against due to their speech and presence of hearing aids.

#### Effects of Stigma

Many others (Archana et al., 2016; Erlen & Garstecki, 2002; Kochkin, 1993; Wallhagen 2010) have found that those with hearing loss still feel stigmatized, regardless of how outsiders perceive the hearing loss. It is more difficult for the stigmatized person to be able to look past the stigma than an outsider. There have been multiple studies analyzing the effect of stigma as it related to those who are in need of hearing assistive devices.

Archana, Krishna, and Shiny (2016) conducted a study and found that those with a hearing loss rejected hearing aids due in part to stigma. They surveyed 100 individuals with hearing loss about why they rejected hearing aids. The most popular reason for rejecting hearing aids was due to "attitude and awareness". These results are summarized in Figure 1. The

“attitude and awareness” category, which was the most common, included looking old, feeling ashamed and inferior, and viewing hearing aids as a sign of weakness and handicap.

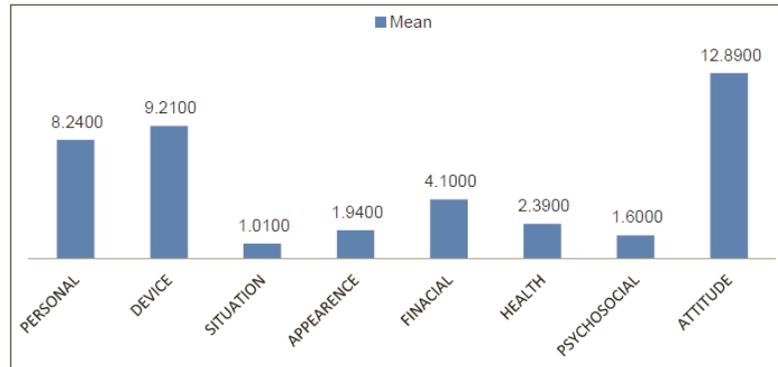


Figure 1: Individual factor analysis (Archana et al., 2016).

Since the older population is more affected by hearing loss than anyone else, it is not surprising that younger people with hearing loss feel stigmatized more than the elderly. It is less common to see a teenager with a hearing aid than an elderly person, which is part of the reason why younger adults with hearing loss feel more stigmatized. Erler and Garstecki (2002) conducted a study in which they investigated the perceptions of stigma related to hearing loss in women of three different age groups. The age groups were younger women 35 to 45, middle aged women 55 to 65, and older women 75 to 85. Results showed that the group with the younger women perceived hearing loss related stigma more negatively than the other two. Similarly, the perceptions of the older group were most positive (Erler & Garstecki 2002).

Kochkin (1993) conducted a similar study which investigated the reasons why people with hearing impairments rejected the use or purchase of hearing aids. Overall, he found that one of the main reasons for non-usage of hearing aids was the negative images that are accompanied with wearing one. In fact, more than 40% of the participants reported that stigma was a reason for not purchasing. Results of the study, as shown in Figure 2, also found that stigma related to hearing aids was a reason for non-purchase was the highest in the 35-to-44-year-old age range and decreased with the older age groups. It is also important to note that the 35-to-44-year-old age group is the group with the highest number of non-owners of hearing aids (Kochkin, 1993).

In a later study by the same researcher, the percent of respondents who rejected hearing aids due to stigma was 48% (Kochkin 2007) as compared to the 40% in the 1993 study.

Wallhagen (2010) reported that “perceived stigma” was a factor in

multiple decision making processes related to hearing loss. The term “perceived stigma” is important to note here since it indicates that it is what the hearing impaired person *felt*, not exactly what was happening. This stigma led to three other experiences: alterations in self-perception, ageism and vanity. Alterations in self-perception could mean changing from feeling able to disable, or intelligent to dumb. Ageism is used here to describe the link of hearing loss to getting older and the general public’s perception of the elderly. It is common for hearing impaired people to reject hearing aids on the claim that it “makes them look old”. Vanity was also noted in this study with many of the participants not accepting hearing aids based on appearance. It is not surprising that vanity is an experience related to the stigma of hearing loss because of how hearing loss is presented in the Western culture.

The way products and services are advertised can influence a purchaser in ways that he or she may not even be aware. Most hearing aid companies put extra emphasis on how small and inconspicuous their hearing aids are in their advertisements. This sends a message to the readers or watchers of the advertisements that noticeable hearing aids are a bad thing and that someone should only want one that is not noticeable. A participant in Wallhagen’s (2010) study, when asked if he thought there was a hearing aid related stigma, responded by stating

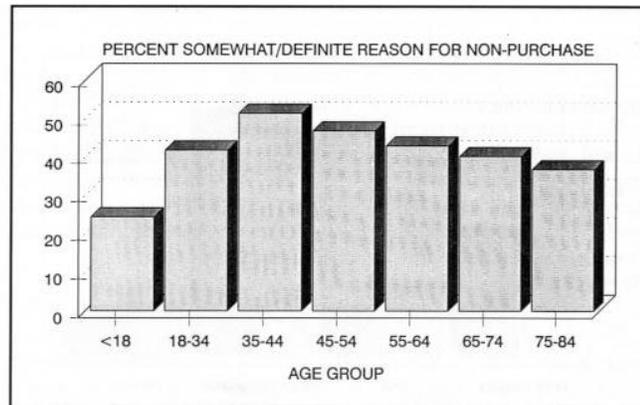


Figure 2: Percentage of consumers, by age group, not purchasing hearing instruments because of stigma (Kochkin, 1993).

I think there is, still, yeah. I think they'll be a time. That's why the big trend is to get the hearing aids shoved up inside your canal...I don't think they'd go to so much trouble and expense unless there was a stigma to it. (p. 72)

This type of advertisement can be contrasted to advertisements for eyeglasses. The style for eye glasses now is larger with darker frames, essentially more noticeable. The wearers are purposely drawing attention to their impairment. In this case, vision impairments are used to make fashion statements while hearing impairments should be concealed.

Stigma is also a main reason for not seeking help when help is needed. Southall, Gagné, and Jennings (2010) conducted a study to better understand how stigma influenced the help seeking behaviors of adults with hearing loss. There were ten participants in the study with an average age of 65. Each individual had an acquired progressive hearing loss. The participants were asked a variety of questions, in an informal setting, ranging from broad to more specific. The questions were designed to identify how stigma may have affected their help seeking. The interviewer sought narratives and personal experiences. The reason for this was to acquire more reliable information, rather than repetitions of things commonly said at peer groups. The results of the study present three themes that occur in the help seeking process. "The three themes are: (1) a gradual build-up of negative stress; (2) Critical juncture one: mounting losses lead to unmanageable stress and an abrupt intensification of the need to seek help; and (3) Critical juncture two: build-up of positive energy initiates involvement in peer support group and transformation" (p. 808). The build-up of negative stress included negative views from society, friends, and family members not understanding, and everyday activities becoming increasingly more difficult. Next was "critical juncture one." This juncture includes losses in social life and workplace and how those losses impacted the individual. It also includes the inability to cope

with the stress any longer and realizing that something needs to be done about it. And lastly, “critical juncture two” involves the positive influences from recently joined support groups, and how that affected the individual. These positive influences could include taking off some of the stress or replacing the losses with something else. After these three themes is when the patient will likely seek help for the hearing loss.

### Overcoming Stigma

This stigma is what needs to be overcome before any progress can be made in the patient’s treatment. Overcoming stigma is not something that can be done overnight: it takes time and effort before the patient can overcome the feelings of being stigmatized. One way this can be accomplished is through the use of group therapy. Héту, as summarized in Gagne et al. (2011), described a two-step Audiologic Rehabilitation (AR) program designed to help those with hearing loss overcome negative feelings associated with the hearing loss. The first stage of this process is meeting with other people with hearing loss to share experiences, struggles, and helpful hints. The second stage involves applying skills learned in group sessions to social interactions outside of the group with those without hearing loss. The first stage of this program, the group therapy, is especially helpful in overcoming the negative feelings associated with hearing loss.

Peer support groups can help the participants realize that they are not alone and there are others going through the same things as them. A “normalization process” is started by understanding that the feelings they are having are typical of most people with hearing loss (Gagne et al., 2011). They develop a more positive attitude about themselves and are more likely to seek help (Southall et al., 2010). Participants may also experience a decrease in perceived handicap. This is evident in a study conducted by Getty and Hetu (1991) which examined the

outcomes from group sessions. Comparing answers from a handicap questionnaire before and after group interventions showed a significant decrease in perceived severity of the hearing loss. Also, participants in a peer support group will likely learn strategies to succeed during interactions (Gagne et al., 2011).

Participation in peer support groups can also help replace things lost from the hearing loss, such as losses at work or with friendships. One respondent from Southall's (2010) study shared her experiences in her support group:

I was very much looking for new friendships. But I wanted friendships with people who would understand, that I wouldn't have to constantly explain it to them... I really didn't want to go out into the hearing world, but I wanted friendships and companionship. I wanted someone who I could go to the movies with. Or have dinner with. So these people that I found in the [mentioned a specific chapter of a peer-support group association] chapter were it. (p. 810)

This is an example of peer support groups replacing friendships that may have been lost due to the hearing loss.

Once participants feel comfortable in the peer support groups, they are encouraged to apply those skills to interactions with friends and family who do not have a hearing loss. During this process, the participants learn effective ways to let their conversation partner know about their hearing loss and how to use communication strategies that best fit the situation. The improved communication leads to a more positive self-image. Once the program was completed, participants were more likely to adopt the usage of hearing assistive devices (Gagne, 2011).

Stigma related to hearing loss has existed for many years and is likely to continue for years to come. However, providing the public with information on hearing loss and hearing

assistive devices may make an impact on stigma and how hearing loss is perceived. Having the knowledge on the subject and being able to imagine oneself in the shoes of a person with hearing loss could make that person less likely to stigmatize. Having sufficient knowledge may also help persons with hearing loss as well. They should know what options are available and how much treatment may be able to help them. If the public had more information and knowledge on the subject, there could possibly be a decrease in hearing related stigma.

### Conclusion

Stigma has been, and continues to be, one of the leading causes of denial of hearing assistive devices. There have been many studies that have found that stigma makes a significant effect on the individual with hearing loss in regard to seeking help, purchasing hearing aids, and even participating in social interactions. With some help, there are ways to overcome this stigma, though. It is important for audiologists to be aware of this stigma and to what degree their client is affected by it. Understanding patients' perceptions of themselves and how they think others perceive them is necessary to be able to provide the most effective counseling and treatment.

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