

Assisting Students with Progressive Hearing Loss

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Abstract

College students with progressive hearing loss encounter many changes in their lives. These changes are occurring during a time when they are developing their social and vocational goals. Research has identified adjustment themes that are experienced by persons with late onset or progressive hearing loss. Different theories on the grief process that describe the emotions that may be felt by a student with decreasing communication skills exist. This paper describes the adjustments experienced by a person with progressive hearing loss, information about the grieving process, and resources that may assist professionals working with this student population.

Assisting Students with Progressive Hearing Loss

Zeizula and Meadows (1992) identified five adjustment themes late-deafened individuals experience as they go through the process of losing their hearing. Understanding these themes may help disability support services providers better assist and support students experiencing a progressive hearing loss. As a deafened adult, I would like to share with you my experiences of progressive hearing loss while in college and relate those experiences to the noted adjustment themes.

The first adjustment theme is Emotional Responses. There are many emotions and feelings people experience while losing their hearing. I received my first hearing aid when I was fifteen. When I found out I had to wear a hearing aid, I was extremely upset. However, I was raised in a family where we did not cry, and my parents' philosophy was that things could be much worse. I now know that crying would have helped me deal with all those emotions at that time. Instead, I saved it for many years later.

I also felt a lot of fear. I was constantly worried that I would lose more hearing, despite assurances from ev-

eryone that I would not. Perhaps it was just intuition, as I did eventually lose all my hearing. Many students also feel guilty about their hearing loss. They feel they may have done something or not done something that contributed to the loss. Many people feel angry and go through the emotions of grief and loss, discussed below. These emotions also include denial and depression. Hearing loss affects self-esteem; often students will not feel good about themselves yet appear happy and adjusted. Regardless, the emotional roller coaster exists, and in a progressive loss it can appear time and time again after each successive or substantial loss.

The second theme identified is Secondary Losses. Communication is the primary loss, but – due to this – there are many secondary losses. In my case, hearing loss also caused me to have balance problems. As I was gradually losing my hearing, I would become very dizzy and have severe vertigo attacks. I was put on Antivert, which then caused me to feel somewhat confused and a bit depressed. As a student, I wanted to socialize, date, and have fun with other students. The hearing loss and the hearing aids made that quite a challenge. I joined a sorority at Ball State University, and I remember going to fraternity parties. I figured out how I could sit or stand next to the speakers at the party and be able to converse fairly well. I would turn down my hearing aids, and people speaking to me would turn up the volume of their voices and talk so they could hear themselves talk. This then enabled me to hear and understand them, and, if I could not, it was not a big deal, as the music was so loud anyway, which served as an appropriate excuse. I also remember a date I had in which a man proceeded to tell me how women enjoy fingers in their ears. He was absolutely shocked when he found out there were two hearing aids in mine! I never heard from him again, and the rejection for that reason was painful.

These experiences add up to a negative view of hearing loss and self. I would wear my hair very long so that no one could see my aids. I did not know of anyone who had them; actually, every so often – when the wind would blow my hair back – people would comment that their ancient relatives used to wear them shortly before they died at the age of 110! These were little secondary losses that added up. They were all considered losses for me, even though professionals who work with deaf students may not look at it that way. I remember not being able to hear the alarm clock during my senior year of college. I would wear the aid to bed in order to hear it.

I found I could not participate in class as well as I had been doing. One day the battery of my aid died; I refused to replace the battery in front of everyone, so I sat there in silence. The professor, who rarely called on me, happened to do so at that time. In the midst of all these losses, there was really no one to whom I could turn. I was unaware that there was a disability specialist on campus; furthermore, still ingrained in me was the philosophy I had grown up with that would not allow me to process these losses.

Confusion of Identity is the third theme Ziezula and Meadows (1992) identify. Looking back on my life, having experienced progressive hearing loss, I realize how important this identification process is in terms of finally accepting one's hearing loss. Not only was I having trouble identifying myself, but others around me would identify me a certain way, and I would question who I really was. I had grown up identifying myself as a person with a slight hearing loss. That is the way my family chose to identify me; therefore, I used it for myself until I became deaf. During my senior year of college, my hearing loss dropped from 45 db to 75 db in my good ear. I had no response in the other ear. At the urging of a professor, I finally went to the speech and language clinic at Ball State. At that time, they told me I was "legally deaf." I had no idea what that meant and was not told what to do with that information. I reverted to calling myself a person with a hearing loss. I struggled with this issue for many years. It was not until I finally lost all of my hearing fifteen years ago that I could finally call myself deaf and teach those close to me to identify me that way as well.

The fourth theme, Acceptance, is something a student with progressive hearing loss may have to do repeatedly. As I mentioned before, with progressive hearing loss, one needs to go through the loss process and finally accept that loss, and then it may happen all over again. I never dealt with the fact that I had this loss. A turning point for me was finding someone in college whom I could trust and to whom I could talk. I was majoring in Deaf Education and chose a very well-respected professor I felt I could trust. She was the only teacher I had in four years at Ball State with whom I shared my hearing loss. I decided I needed to talk to someone and asked if I could visit her. In her office, I honestly spoke about my fears, my sadness, and my concern about losing more hearing. She cancelled class (something she had never done) and took me to the speech and hearing clinic. Afterwards, I was distraught but still thinking that things could be worse. She sat me down and, for the first time, gave me permission not to like it. That was a defining moment for me and has helped carry me through my hearing loss journey. I felt so much freedom and experienced the opportunity to begin to heal from the internal struggling I was experiencing. I was finally able to explain my hearing loss to people in terms both others

and I could understand. I did not have to like it and did not plan on liking it anytime soon.

The last adjustment theme is the need for Competent Professional Assistance. There is a need for training professionals to understand late-deafness. As professionals, we often think if we can work with culturally deaf students, we can work with late-deafened students. We think if we give sign language classes to the late-deafened student or a hearing aid to the severely hard of hearing student, then everything is fixed. Frankly, these are myths. All staff should be trained, because there are students sitting in classrooms with hearing aids that do not know what to do and are not asking for support. There are students that do not know what support is available to them and that may not know there is a disability coordinator on staff.

There are many ways in which disability support services providers can help students with progressive hearing loss. The Northeast Technical Assistance Center (NETAC) has published a fact sheet called "Working With Students who are Late-Deafened." Self Help for Hard of Hearing People, Inc. (SHHH) has also published a list for hard of hearing students through NETAC.

Grieving

The literature on disability and grieving is sorely lacking, particularly around prevention and intervention or facilitation of the process. Relevant materials are noted in the reference section to assist readers who want to learn more about how to work with students who are dealing with issues of loss and grieving.

Our culture is not kind to those who are struggling with the forces and feelings of grieving:

In a culture that emphasizes the accomplishments of independence rather than connection and celebrates the myth of personal mastery over all adversity, the experience of grief, which exposes our deep attachments, our human interdependence, and our true vulnerability in the hands of fate, is as unwelcome as death itself (Shapiro, 1994, p. 4).

Learning about disability is learning about grieving and change. From that basis, a look at some of the concepts one can use in training rehabilitation counselors with an expertise in deafness and hearing loss follows.

Students who are deaf or progressively losing their hearing are losing their sense of self, ability to communicate, and dreams about their future. All people have dreams – more than simply the dreams about marriage, having children, and being successful in work. One

dream, for instance, may be to stay healthy and live a long and productive life. Another may attach people to their religious beliefs. These dreams give meaning to and direction in life.

People also attach to other individuals in their lives – real, profound connections to relationships. This also makes them vulnerable, however, since attaching to a person introduces the risk of loss through death, illness, divorce, or rejection.

When events in life, such as hearing loss or deafness, cause these dreams to be shattered, one's dreams are lost, and individuals feel disconnected and lost, as if they are wandering through a dark void. This is often a response to losses that change one's core identity. It is an experience of many powerful and confusing feelings – feelings that need to be shared with significant others in order to do the work needed in order to learn and grow from losses.

As a culture, we expect the grieving to last a set length of time. People want a quick fix, but this is not the case. President Bush's strong message right after the terrorist attacks of 9/11 was "get back to normal." There are good reasons for this directive, but it is also a cultural expectation. People who have gone through a loss know that there is no such thing as a quick fix; if they do believe it exists, they may think that there is something wrong with them, because they may have not been able to find it for themselves.

There is also an expectation that the people closest to an individual should be the best support, but this is not necessarily always true. There is a notion that the more that someone needs to be heard, the less likely s/he is able to hear about someone else's needs. There is no greater need to "fix" or "cure" than in the family when a member is hurting. Families and even professionals may tell the student, "Don't worry, it will be okay" or "It really could be worse." Families want to support, but they often simply do not know how.

People who experience a loss are often not aware of how it will affect them in the long run. People will hold on to things the way they used to be, such as sitting in a classroom without any assistance, something to which they are accustomed. Even though people may try to help them, they will find arguments that resist the help. At the same time, students with progressive hearing loss experience a need to find some way to "fill the void" of their hearing loss:

When change happens, something ends. Immediately, people want something else to begin. They want something to suddenly fill the void that the ending created. If we move too quickly to fill the void with new beginnings, underneath, the neglected transitions and

unresolved ends fester (Woodward & Bucholz, 1987).

This is an issue that may arise for disability support services providers when working with students. If they are losing their hearing, they want something to put in its place, and they want it fast.

People believe that there are steps and stages in the grief process. This is a misconception, and – in part – is another cultural expectation or "lens" through which to view the process. This perspective of grieving "pathologizes" the process by identifying the feelings of grieving as problems to be solved. It is, indeed, a medical model where people need to be "fixed" or "cured" of their grieving.

Transition Therapy is a model that views grieving as a *non-pathological*, growth-producing process. The painful feelings of grieving are not seen as problems to be solved, but instead they are opportunities to compel the individual to reassess oneself, one's dreams, one's sense of value and worth, and one's direction and purpose in the world. Each part of the process comes as a wave, and they come as they are needed. When each of these feelings wash over a person, they do not follow a pattern, and there can be a lot of confusion and discomfort.

While there may be no specific "order" to the feelings of grieving, there are forces that are preparatory to active grieving – denial and anxiety. People have little tolerance for denial as a coping strategy. Denial is not typically problematic, except to those around the person who has experienced the loss. It is a coping method that professionals think is pathological, but I think that it is a very positive and functional thing. It buys you time to find the external resources and the internal strengths to deal with the impacts and realities of the loss. Outside resources include a notetaker, counselor, fellow students, or a secretary who takes the time to ask you how you are doing. Internal strengths relate to your own recognition of how you have dealt with previous losses and challenges and connecting with those abilities and strengths that pulled you through.

Anxiety, while appearing to be a negative and unhealthy reaction to loss, provides the energy necessary to push one forward into self-exploration and new awareness. It is not necessary to try and calm people who are anxious, but it is helpful to let them know that their anxiety is a message to them that an important piece of knowledge or discovery is coming to the fore. These new bits of discovery come together in developing a new sense of self in light of the loss.

Once the denial and anxiety have fulfilled their function of easing one into this reality and energizing the student for further self-exploration, the work of active grieving begins. Within the realm of active grieving, one experiences four feelings states: anger, guilt, depression, and fear. Like denial and anxiety, each of these feeling

states provides the medium in which people examine specific beliefs and assumptions about themselves and their places in the universe.

When someone experiences anger, what they are questioning is: "Why me? Why not another person? Good things to happen to good people, and bad things happen to bad people, so why is this happening to me? What are the rules about fairness and justice in the world? Do these rules exist, or are there none? If there are no rules of fairness, I am in chaos and I am vulnerable." In anger, people examine issues of morality and ethical behavior. Does one choose to be a person of morals and ethical standards simply to ensure good things will return? In light of loss and through this search for meaning, it may be that we choose to be a person of morals and ethics regardless of whether or not good things will follow. This is one example of growth and maturity out of the struggle of grieving.

Depression expresses a concern about competency and self-worth. Each person develops standards for competency, personal worth, and potency. These standards are shaken or perhaps shattered in light of hearing loss. Questions asked in this feeling state may revolve around questions such as, "Can I be deaf and still be competent? Am I still a person of potency and value in the universe?" Often, we bring with us from childhood very unrealistic definitions of competency. These are typically shaded and modified over time in a gradual process. Acquired deafness and progressive hearing loss completely overturn this definition, leaving confusion and depression in their wake.

Guilt, which is often overlooked or dismissed as "irrational," is a very genuine feeling state based on one's sense of cause and effect and of one's power and control in the universe. The question "why" calls for an answer. When there is none, in pain and confusion one must assess the limits of his/her own power to control the hearing loss, as well as other difficulties and losses in life. Which is more unsettling – to find there is no rhyme or reason as to the "why" of losses or to accept some sense of responsibility for "causing" – or at least not doing whatever was necessary to avoid – the loss?

Finally, one's fear is a reminder of the vulnerability of attachment and loss. It compels the individual to examine the decision whether to remain alone, safe from the pain of losing, or to attach again and face the risk (perhaps the certainty) of loss.

What can disability support services providers do to help? Two things are of highest value in being a supportive companion for the student who is struggling with the empty void and the very painful and frightening feelings of grieving. First, it helps to become more informed about and comfortable with the process of loss and grieving as a growthful and necessary experience shared by all humanity. Once we are less afraid of being in the presence of someone's grieving, it becomes much more likely that forward movement toward new dreams will

occur. Secondly, take the time to listen to students' stories, to why the person feels angry, depressed, guilty, or afraid. These are not problems to be solved or fixed. They are natural feelings that need to be shared with a significant other. In this case, that significant other could quite possibly be a disability support services provider.

Resources

The Association of Late Deafened Adults (ALDA) has a Web page at www.alda.org, providing information that may be of assistance to students. These resources include membership information, information on ALDA groups and chapters in the United States, an email chat group, and publications that may be of interest.

The email chat group is not a live discussion forum but an email exchange group. People can discuss various concerns they may have related to hearing loss. Some concerns that have been discussed include coping with Meniere's disease, neurofibromatosis (NF), and other related illnesses. People exchange coping techniques and share therapies or medications that have been effective for them. This important chat group allows deafened individuals to meet and talk with other deafened people in a non-threatening environment.

The publications available from ALDA include the proceedings of past conferences and a book entitled *ALDABest*. This includes a selection of the best articles that were printed in the first ten years of *ALDA News*, the quarterly ALDA newsletter. The book contains articles that are humorous as well as articles that deal with serious situations, such as family holiday gatherings. Again, reading the book is non-threatening for the student and may assist them in developing coping skills or becoming assertive enough to become involved with social groups and organizations.

People interested in obtaining more information about ALDA may utilize the following contact information. E-mail addresses for ALDA board members are available on the Web page.

Association of Late Deafened Adults
1131 Lake Street, # 204
Oak Park, IL 60301
877-348-7537 V/FAX (United States only)
708-358-0135 TTY

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