Paparella: Volume IV: Plastic and Reconstructive Surgery and Interrelated Disciplines

Section 2: Disciplines Closely Associated With Otolaryngology

Chapter 27: Psychological Approaches to the Patient with Hearing Loss

Kenneth Z. Altshuler

Audition is a distance receptor that scans 360 degrees and constantly separates figure from ground. It brings with it melody, the subtlety of nuance, and the spoken word. Loss of any of these is painful, and adjustment to such loss difficult. The psychological reaction to hearing loss is complicated further by factors such as the degree of impairment, at what time in the life cycle it occurs, and whether it is acute or develops chronically.

In each of the circumstances discussed in this chapter, an understanding of the patient's situation and reaction can allow the otolaryngologist to play a crucial and appropriate role.

Early Profound Deafness

Profound deafness may be defined operationally as a level of loss that makes auditory intercourse with the world impossible. Generally, losses above 80 dB across the speech frequencies are necessary for this to ensure. Occurring at birth or before speech is established, such impairments have pervasive consequences. The loss limits the acquisition of language at the normal time and by the usual route - imitation at the template of whatever words or language is heard. It demands long years of special education to remedy, and the best of speech and lip-reading training delivers about one-quarter of those affected to a position of oral fluency and equivalent lip-reading skills. Since a considerable, indeed inordinate, amount of knowledge, training, and general experience is brought to us by audition, its absence cuts down enormously on the range and quantity of experience available. Moreover, profound deafness interferes significantly with the natural ease of the child-parent relationship. When deafness is discovered, it confuses the parents, makes them guilty, and confronts them with a sudden stranger.

In about one-half of the cases, deafness is not diagnosed until well into the second year of life. Even before the diagnosis is made, parents are quite troubled. The normal child is soothed by any human voice at 2 weeks of age, prefers a female voice at 3 weeks, and particularly responds to its mother's by the fifth week of life. These responses are missing in the deaf child, who may seem inattentive and later difficult to train. Faced with ambiguous cues, parents become uneasy. They may visit a physician and be briefly and falsely reassured when, by virtue of vibration or some residual hearing, the child responds to the doctor's loud clap. Since deafness is grossly invisible and pediatricians often are not trained to be alert to it, the average lag between suspicion and diagnosis is about 10 months in cases of profound deafness, and more when deafness is only severe. One study reports 60 per cent of parents to have had four or more consultations before the diagnosis was made, with one-third of the patients having been assured by the first doctor that deafness was not present.

The initial reaction when the diagnosis is finally made may be relief, but it soon gives way. Knowing what is wrong is better than confusion, but as with any handicap, parents have a difficult time accepting it. They may become depressed, seek to place the blame, and deny the handicap. In the last noted connection, educational biases have too often lent an unwitting hand. By emphasizing solely oral-aural educational approaches, educators have abetted parents' desires to believe that their child will be no different from others despite the problem. The result is to delay a family depressive reaction until the deaf child is adolescent, when the social advances of hearing children demand language and leave him clearly behind, and when limited language skills are no longer deniable.

Otolaryngologists have several functions in this scenario. The easiest is diagnosis, since in this role they are most skilled and comfortable. Educating colleagues in pediatrics to earlier alertness to the possibility of hearing loss is another role for which they are well prepared. They may also be involved in prescribing or supervising the fitting of hearing aids and helping the family to see a psychologist or psychiatrist if it is difficult to get the child to accommodate; this may be somewhat less familiar ground. Least comfortable of all will be the role of otolaryngologists in helping the family to avoid their denial and to accept and deal with the handicap appropriately. Nonetheless, knowledge is scarce and conflicting opinion so easily available that this responsibility cannot be avoided. The authority of the otolaryngologist may be necessary to help the family toward acceptance and toward the course designed best to support the natural maturational tendencies of the child.

In the past 20 years, many studies have documented that the deaf children of deaf parents are more socially mature and think better of themselves than the deaf children of hearing parents. The difference is, of course, that the deaf parent communicates easily with the child by means of manual language, and has a natural and age-appropriate relationship. Recent studies also demonstrated the obvious: that the deaf child exposed to sign language develops a vocabulary and grammatical structure comparable with, and on a timetable comparable with, that of a hearing child; and that sign language skill is not a disincentive to learning written or spoken language. Indeed, from toddler age on, communicative competence is better when manual language is available. It is cogent and touching that mothers are also found to be less intrusively didactic and correctional, and that both mothers and children smile and laugh more frequently when total communication is employed than when communication is oral only.

The results of such studies were predictable. That they were necessary attests to the tenacity of wishes to avoid manual language, the main visible sign that deafness is present. Such desires to deny the handicap make the counseling of parents difficult. The doctor should patiently hold to simple logic: that manual language allows communication to take place at the time in life when evolutionary wisdom has programmed it; that the action of parents in learning it opens a relationship with their child that would otherwise remain closed; that total communication means as much emphasis on oral methods as the child can profit from; and that desires to wish the handicap away are understandable and warrant sympathetic concern, but are ultimately both unsupportable and capable of doing harm.

The same approach is to be advocated when some modest residual hearing is present, and for the same reasons. No amount of deafness indicates a compromise of intellectual potential. The combined approach supports the likelihood that the potential is achieved. It is not an abandonment of oralism; it means all the oral and lip-reading practice that the child can use, plus manual language, and thus the opportunity to have language at the time that language normally develops.

In cases of congenital profound deafness, other handicapping conditions are sometimes present. This is still more likely in prelingual adventitious deafness, in which the condition causing the deafness, or its treatment, leaves other residua such as brain damage. Taken as a whole, one-third of children with profound prelingual deafness have at least one additional handicap, and males are slightly more likely to be affected than females. The pediatrician generally is the primary care physician in such cases, and otolaryngologists' role is ancillary. At times, however, the lead may be thrust upon them, and they should therefore be aware of social agencies in the locale for psychometric evaluation and educational placement of the multiply handicapped. It goes without saying that the approach to the parents in such cases should be sensitive, delicate, and sympathetic to their confusion and plight.

A word is in order also about the fitting and use of hearing aids. On the very young they are a foreign body, and it may take much patience and many serial attempts to help the child accommodate to their use. The child can generally get used to them, slowly, if the aids are not too uncomfortable and the parents are gently persistent and matter of fact. Unmanageable recalcitrance suggests either a poor fit or ambivalence on the part of the parents. Referral to a child psychiatrist or child psychologist should not be avoided when the physician suspects such problems.

The otolaryngologist should make a similar referral if the family cannot accept or has great and evident difficulty dealing with the advice earlier recommended. The most common reaction to loss is depression, and discovery of handicap in a child represents a loss of many potential aspirations. An over depressive response is usual, and time is required to come to terms of acceptance; however, defensive denial, ambivalence, irritability, or resentment toward the bearer of bad news or good counsel may be means of warding off the depressing blow. Although it is easy to be advised of such possibilities, doctors generally find them difficult to endure in practice. Being raged at for advice that is good but not what is wished for is uncomfortable; physicians, whose life aim is to be actively helpful, are prone to guilt or counteranger when they must confess helplessness or admit that a loss is irreversible. If doctors feel enmeshed in such circumstances beyond what their training prepares them to deal with, they should make the appropriate referral.

Hearing Impairment after Speech Is Established

It is obvious from the foregoing that in early profound deafness the parents are the primary object of counsel and interaction, and the doctor in a way has less to do with the subject affected. When speech is established, the child is an older toddler or more, and both he or she and the parents are in the foreground as patients. Both react to the hearing loss, its diagnosis, and its treatment.

Again, since the handicap is invisible, problems and confusion begin before referral. There often is poor speech, poor school achievement, and complaints of poor attention span or labile mood. Irritable behavior and apparent resistance to authority are also common. Perceptual handicap must be distinguished from low IQ or emotional disturbance. Such discrimination may require the help of specialists from several disciplines.

The audiologic diagnosis and the treatment itself are reasonably straightforward and often curative: amplification and special educational assistance as indicated by the extent and time of development of the loss. Milder and later losses will be aided by amplification alone; earlier and more severe impairment may require special education or special schools. Again, the otolaryngologist should be knowledgeable about the facilities and agencies in the region and able to interact comfortably with them. A vast majority of impairments in this age range are chronic in development and are present for some time before discovery.

In terms of psychology the situation is traumatic for both child and parents, and may reverberate throughout the family. If the loss is chronic and was long in discovery, the child is often already considered strange or difficult. If the loss is acute or discovered quickly, the child endures a sharp change and loss. In either event, there is the stigma of difference. The loss is an impairment, and the uncomplicated reaction to it is in proportion to its degree. That is, the greater the loss, the more special help is necessary and the harder it is to adjust to the difference. Self-esteem falls, by virtue of problems before the diagnosis is made and the sense of difference once it is known. Reactions can be made worse by the intensity of the stigma, from hearing aid to special classes or involuntary relative sequestration from former peers. In highly aspiring families, a relatively slight impairment may bring severe reactions in the child, as even a mild deficiency looms larger when perfection is the goal.

For parents the situation again brings sadness and disappointment for their child and constitutes a blow to their own narcissism as parents. They can help their child adjust, and their own adjustment is eased, to the extent that they can see the child as a separate being and not an extension or reflection of themselves in terms or procreative prowess or personal hopes for excellence. No parents accomplish this easily and one must allow several months to a year for an adjustment to be made. Clear information about the extent of the hearing loss, its implications for school (ie, the requirements for help and the level of achievement possible), and the presence and extent of other damage (eg, balance, vision, brain damage) can be most helpful. The physician should expect that repetition of information will be required and that interaction with other agencies on behalf of or in consort with the family will be necessary. Patience and empathy will be strong allies in his efforts to assist. If the difficulties in mood or behavior of the child persist beyond a few months without moderation, a depressive reaction should be suspected (see later in this chapter) and proper referral made.

Hearing Loss in Adulthood

The stereotype has developed of elderly people as irritable, given to surly outbursts, and sure that others are talking about or plotting against them. The stereotype has it that they are hard of hearing. Such reactions to hearing loss are not uncommon, but there is little to support the stereotype as typical or particularly widespread. What it represents instead is one in an array of possible elaborations of the depressive reaction to loss of hearing.

The range and causes of hearing loss in the adult have been detailed elsewhere in the text. For our present purposes we can group impairments as acute and chronic, and can omit milder or unilateral losses that cause no interference in social or vocational function.

An acute and profound loss is undeniable, whereas admission of a chronic, slowly increasing one may be warded off. The former may cause shock and withdrawal as one tries to cope with a sudden alteration of the tools to adjust to life's circumstances and a change in circumstance as a result. The loss of background sound and its constant stimulation often leaves a sense of emptiness. The world seems dead and lifeless. Feelings of helplessness and helpless outrage against circumstance may yield a clinical picture of agitation, humiliation, or depression. Even in individuals who apparently cope quite well, such feelings are often present. Awareness of their inevitability can sensitize the otolaryngologist in dealings with the patient. Over time, and with better adaptation to the real costs of the situation, such feelings generally moderate.

Most studies of the psychological consequences of acute loss were made in hearing-impaired soldiers during and after World War II. Symptoms of anxiety, irritability, or depression became long-standing and well entrenched in one-quarter or less.

Patients with a chronic, slowly developing loss have the same problems to face, but the insidiousness of onset allows for a lack of awareness, a denial, an attribution to others of talking too softly, and an irritability in the face of such perceived lack of consideration. An unconscious awareness and anger that the fault is within themselves may heighten the querulousness of the hard of hearing. From this combination of feelings develops the stereotype described earlier, but it does not have to be so. Many simply face the fact of their loss, accept what remediation is possible, and go on about the business of life, albeit with some unhappiness about the problem.

The difference in reactions depends on the person's personality and what the loss implies to him or her, in addition to its real extent and the consequent realistic limitations. Hearing loss can be perceived as a cosmetic insult, an affirmation of age, an affront to personal omnipotence, a limitation in armament for the combat of life, an increase in vulnerability to attack, or a shameful personal deficiency. Such interpretations may be made unconsciously and regardless of the extent of real damage and the amount of real rehabilitation required. Reactions are in proportion to the power of these interpretations and may interfere with the ability to cooperate with rehabilitative efforts. In healthy people, the milder losses are accepted with relative equanimity and the more severe ones are adapted to. If the needs for perfection or power are excessive, however, the person is prone to more difficulty in adjustment, at times too the point where the struggle between resignation and resentment becomes unceasing.

Depressions are thought of presently as an ubiquitous fact of life and mood, and as a medical illness. None of us are immune to shifts of fortune, and all waver from time to time in our state of contentment or unhappiness. Depression as a medical illness, however, is more than the occasional unhappy mood or the waxing and waning of dissatisfaction and sad feelings as one grapples with a particular problem of life. Its criteria have been operationalized as including five of the following symptoms, at least one of which is either a depressed mood or diffuse loss of interest, relatively unmoderated and without surcease for a minimum of 2 weeks: depressed mood; markedly diminished interest in all activities; significant weight loss or gain when not dieting; insomnia or hypersomnia nearly every day; psychomotor agitation or retardation; fatigue or loss of energy nearly every day; feelings of worthlessness, or excessive self-reproach or guilt; difficulty in concentration; and a preoccupation with thoughts of death or suicide. When patients have the syndrome typified by these criteria, they have a major depressive disorder. About 80 per cent of such cases are treatable with success by medication or a combination of medication and psychotherapy. Such treatment can be successful even when another medical illness is a clear precipitant of the depressive reaction and, although there are few specific data, should also succeed when reactions are precipitated by hearing loss. The physician will want to observe patients carefully and respectfully give them the opportunity to come to grips with the loss on their own terms and in their own time. However, when he can see that the criteria of major depressive disorder are met, or if time has elapsed and he remains uncertain, referral for psychiatric consultation is in order.

Children, long thought of as immune to depressions of comparable quality, are in fact similarly prone to them. Diagnosis is still more difficult, however, since children are likely to demonstrate their mood disorder in behavioral aberrations rather than describe or complain of it. For these reasons, a particular alertness to the possibility of major depressive disorder is required in children when the reactions to impairment are prolonged or adjustment difficulties appear to be inordinate.