Accessibility of optometric care to the deaf patient: Understanding the communication barrier

Mark H. Baker
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ACCESSIBILITY OF OPTOMETRIC CARE TO THE DEAF PATIENT:

Understanding the Communication Barrier

By

Mark H. Baker

A thesis submitted to the faculty of the
College of Optometry
Pacific University, Forest Grove, Oregon
in partial fulfillment of the Degree of
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Advisor: Dr. J. Rodenkamp
Abstract

The deaf population is not currently receiving adequate optometric care. In part, this is a result of the deaf patient's isolation from the health care system due to an inability to access the practitioner. An increased utilization of Telecommunication Devices for the Deaf (TDD's) by the private practitioner would largely alleviate this situation. Once in the health care system, the deaf patient often does not receive the same standard of care given a hearing patient. The quality of care can be improved if the practitioner has a better understanding of the etiology of deafness and the advantages and disadvantages of the various methods of communication available in the exam setting. While a professional interpreter will usually be the method of choice, individual circumstances will dictate which method is best for a particular patient.
As a member of a primary health care profession, an optometrist has an obligation to administer to the visual needs of the society in which he/she lives. This is reflected in the Hippocratic Oath taken by physicians, and by the statement of purpose put out by the American Optometric Association.4 Part of society, however, has largely been ignored by the optometric community. Vision represents the key sense remaining in deaf people: their bridge to the world. It is vital that it be assessed thoroughly.5 This segment of the population, due to the nature of their situation, has always had difficulty obtaining equal opportunity with the rest of society.6 Ironically, it is this group that can least afford vision difficulties. As optometrists, we should be especially aware of the needs of this group of patients. Thorough, comprehensive care is critical to their well being. Two of the major issues within the optometric community at this time, therapeutic drug legislation and containment of commercialism, are both concerned with the quality of patient care. Some of this concern for quality patient care needs to be directed towards the deaf population. The deaf community simply does not have adequate access to optometric services.7 Reasons for this inadequacy range from misunderstandings about "deaf patients" to lack of understanding of the etiology of deafness and deaf culture. The optometric community needs to address this problem, both as individuals and as a profession. It is not difficult to actively serve the deaf community, provided one takes a little time to learn about the unique characteristics that this group presents.
In general, the deaf population has a higher incidence of vision problems than the hearing population, based on the percentage of complaints within each population. A three year study was performed at the National Technical Institute for the Deaf on the NTID students of the entering classes for 1977, 1978 and 1979. The results yielded an estimated incidence of far acuity problems of 48.7% (N=620), an estimated incidence of abnormal color vision of 4.0%, and an estimated incidence of binocular vision problems of 11.3%. Some students had more than one problem and were counted in more than one category. Combining these categories and eliminating duplication showed that 58.4% of the students had a problem in one or more of the three areas. The visual pathology portion of the study revealed that 31.2% of the students had some type of ocular pathology. (For unspecified reasons N=573 for this part of the study). The four leading diagnoses were strabismus (8.8%), Rubella Retinopathy (7.5%), color deficiencies (5.9%) and Retinitis Pigmentosa (2.3%). Fifty (8.7%) of these students exhibited the types of pathologies for which a periodic examination would be recommended because of the possibility of recurrence or the possible progressive nature of the problem. Forty of these fifty students, however, did not indicate an awareness of their problem prior to the exam. Twenty-one of these pathology cases presented with no other visual complaints. Therefore the estimated incidence of all visual problems among entering NTID students, when eye health as well as eye functioning are considered, is approximately 62%."
The inability to communicate may eventually result in one of two consequences, the first being total lack of care due to practitioner inaccessibility. Deaf patients do not have direct communication to the health care system, either for routine information or emergency care, because of isolation from the telephone. Very few optometric offices are equipped with TDD's (Telecommunication Devices for the Deaf), so a deaf patient must rely on a hearing friend or relative to make the appointment (TABLE 1). For some deaf people this may be too much of an inconvenience. Visual problems seldom present as an emergency situation, unlike many medical or dental conditions. This may reinforce any tendency to delay seeking eye care. Willingness to serve the deaf community on the part of the provider is not necessarily enough. Loraine DiPietro, of the National Academy of Gallaudet College, has said: "A close look at programs and services and their actual accessibility to handicapped persons is frequently enlightening. While handicapped persons may be welcome verbally, the barriers - physical and communicative among others - result in discrimination by practical inaccessibility."

Though figures for adults are generally not available, studies of deaf children indicate that they are not getting proper visual care. One study showed that 47 of 54 children (deaf children ages 4-12 years) with correctable vision were receiving no visually related medical treatment. In a 1978-79 Louisiana survey of hearing impaired students, the majority of the school files contained no record of the students having been given a visual examination.
The second possible consequence of the inability to communicate is inefficient, inadequate, or incomplete care due to poor communication or misunderstanding. Before discussing the potential inadequacies of the communication process in an examination, some comments concerning the etiology of deafness and deaf culture are necessary. A distinction also needs to be made between deaf patients and adult onset hard of hearing patients, those individuals who lose their hearing later in life. This group will almost never refer to themselves as deaf. A recent article in Optometric Management in part discusses this group of patients. The two forms of communication most used in these cases will be to speak louder than normal and to write notes when needed.

Deafness can be separated into two categories depending upon age of onset. The characteristics of these two categories have far reaching consequences. Those born deaf or who become so before language and speech are learned through hearing, are said to be prelingually deaf. Deprived of early auditory stimulus, the prelingually deaf child will usually experience a severe delay in language development. Richard Brill, et al in the article Appropriate Programs, state "Normally hearing children have acquired speech and language by just listening to the conversation of peers and adults in their environment...Usually when deaf children are ready to enter school, their use of (the English) language is limited. Unlike their hearing counterparts, they do not know the meaning of very many words...Not only do they not
know the vocabulary, but they usually do not know how to use these words in structured sequences which transmit meaning to others."

Due to the time prior to recognition of the hearing loss, and the subsequent time spent with various specialists determining the extent of the loss, the child is often two to three years old before signing is first initiated. With hearing parents, the first attempt at sign language is very often signed English, following English grammar, with a sign for each word. While the child may not know some simple English words, he/she may have already developed a large sign vocabulary by the start of kindergarten or first grade. In contrast to signed English, American Sign Language (ASL) has its own syntax, sentence structure, and grammatical rules characteristic of a language. The latter is often learned after the first attempts of signed English, in a residential school setting, such as a state run boarding school for the deaf within that state. The students may be day students only, going home every day after school, or they may live in the dormitories on campus, going home on the weekends and vacations. Those that do not attend a residential school in childhood may not develop ASL skills until the late teens. Postlingually deaf children become so during or after the development of speech and language. This group represents a small fraction of the total deaf population of children, approximately 5% to 10% of the hearing-impaired population, due to improved medical treatment for diseases that formally contributed to hearing loss.

There are essentially three different methods of communication
with the deaf patient. These are respectively lip-reading coupled with the patient either talking or writing, two way written communication, and the use of an interpreter. Each method possesses its own set of restrictions and conditions. Several of the communication methods incorrectly assume that the deaf patient has a good command of the English language. Lipreading requires the deaf person to understand English word order, syntax, and possess a good vocabulary of English words. To communicate with written instructions requires the same skills, but the average prelingually deaf adult reads on the fourth grade level. This limits both the amount of information that can be shared through writing as well as the type of information this individual can understand from the information booklets and other written materials provided by medical personnel. Nancy Ford, of the National Deaf-Blind Information and Resource Center, has noted: "There is a tendency to believe, especially if the client's visual or auditory impairment is not total or profound, that notewriting or speechwriting(lipreading) will be sufficient. This is a misconception and skills in this area should not be assumed." Some people with residual hearing will not be able to function in a hearing manner if the hearing loss occurred early enough in their life. Effective use of residual hearing is highly related to age of onset of the hearing loss, the amount of the hearing loss, and the specific frequencies lost. Writing, in addition to the language problems already discussed, is slow and tedious. Both the patient and the doctor must resist the temptation to abbreviate
explanations, questions etc. due to fatigue. A 1980 survey of health care for the deaf showed written English to be the most common method of communication used, yet one third of those polled felt they were understood only some or very little with this method.\(^1\)

Another commonly used method of communication is to assume that the deaf patient can read lips. In reality very few are proficient lip readers; most do not read lips.\(^1\) For those patients that rely on lip reading to some degree, it is important to realize that only about 30% of English sounds are actually distinguishable on the lips, the remaining 70% being either invisible or identical to other sounds. Attempts to slow down or exaggerate speech for the benefit of the lipreader actually serve to distort the visible patterns of speech. Loraine DiPietro, et al strongly oppose lipreading: "Other factors such as unfamiliar terminology...foreign and regional accents, inadequate or inappropriate lighting...impede the speechreading process...there is no room for guesswork of this sort in the medical setting."\(^2\)

Part of the basis for their position is the importance they place on the case history, as indicated by the following, "The whole medical process of diagnosis and therapy is dependent on precise communication. The majority of diagnoses are made from careful history-taking alone."\(^3\) While originally directed at physicians, it is just as applicable to optometry. This article continues "Getting answers to routine medical questions, teaching a patient about his disease, providing a rationale for therapy and reasons
for patient compliance, obtaining informed consent and explaining alternative therapies all require precise two-way communication. Effective communication is not usually simple. The doctor and patient need to have the most effective means of communication possible available to them.

For many prelingually deaf patients, a qualified interpreter is the most effective means of communication. While it is often easier to use family members or friends, it is usually better to use an experienced, impartial interpreter. In the previously mentioned article by DiPietro et al, she comments, "Confidentiality problems and emotional involvements would mandate caution in such situations because of potential ethical and legal issues. It is best not to use a family member as an interpreter unless the patient specifically requests this and the family member agrees." While signing skills would be very beneficial, caution should be emphasized before assuming responsibility for the entire communication process. The tendency for a hearing person is to sign the same way that they speak, using English sentence structure and grammar. On the receiving end, the average prelingually deaf person may not have sufficient English skills to correctly understand the message. In addition to the potential for overestimating a patient's English proficiency, there exists the question of which signing method or system to use. There are several different systems of signed English in use, in addition to American Sign Language. Each region may have their own signed English system and/or dialect. Interpreters are familiar with
several systems and recognize which system the patient is most comfortable with. This is not an ability even an individual with good signing skills normally possesses. Signing in general is also much more difficult to receive than to send, often resulting in an overestimation of one's skills. It would be very easy for a hearing doctor or technician with only minimal signing skills to be overwhelmed in a one on one conversation with a deaf patient. A hearing person with a even good sign vocabulary but familiar only with a signed English system will likely be quite confused by a deaf person using ASL. While it may be possible to finish an examination, the practitioner who depends on his/her own signing skills, when only minimal, to complete the exam may not have enough information to arrive at the proper diagnosis. Unless truly proficient, it is best to reserve one's own skills for initial conversation and use a certified interpreter during the exam. A list of local qualified interpreters can be obtained from the local office of the National Registry of Interpreters for the Deaf, an organization that provides national certification, which verifies that the interpreter has met minimum educational, and through examination, practical competency requirements. When using an interpreter, speak directly to the patient, not to the interpreter. Be aware that while you are looking at and talking to the patient, the patient will be watching the interpreter. Avoid looking at the interpreter when the interpreter is voicing for the patient (converting the patient's signing into speech). Visual attention should always be directed towards the deaf patient;
listen to the interpreter.

Regardless of the communication method used, it is important for the doctor to confirm the patient's understanding of previous information covered. Some deaf persons will nod their head even when they do not understand, "for fear of offending the practitioner." As a result the deaf patient may ask fewer questions and may feel awkward if they don't understand. The practitioner can aid this situation by having available the communication mode most comfortable to the patient. Advance knowledge concerning the patient's situation will help in this regard, especially if an interpreter is anticipated.

As discussed earlier one of the significant problems facing the deaf population is the inability to directly access the health care system. Telecommunication Devices for the Deaf (TDD's, or more specifically, TTY's) enable a deaf person to place phone calls through the use of typewriter style keyboards. Messages are typed back and forth between the two parties. The system requires both parties to have a TTY device installed on one phone line extension. Legislation just passed in Oregon will provide state funding for the purchase of TDD's for every deaf individual in the state. This is the second state to enact such legislation, California being the other (Two states offered TDD rentals, Texas and Illinois, as of 1980). Several other states are currently considering similar measures. There is available an international telephone directory of individuals and organizations with TDD capability. The 1989 International Telephone Directory for TDD
Users lists 177 medical facilities and 14 optometric facilities with TDD capability. Of these, 28 of the medical facilities and 3 of the optometric facilities are located in Maryland or the District of Columbia, as a consequence of the proximity to Gallaudet College, one of the few colleges predominately for the deaf in the country. Many deaf organizations across the country publish their own local newsletters. Combining the national organizations with the local organizations, schools, and clubs, and the number of publications directed at a readership within the deaf community reaches 400. These are probably better at reaching the deaf community than the Yellow Pages, although this is not a sufficient explanation for the lack of optometric facilities with TTY listings in the phone book. An informal review of the Yellow Pages of 6 large metropolitan areas of the country - Washington D.C., Atlanta, Portland, Seattle, Miami, and Chicago - found only 7 TTY numbers for optometric or ophthalmological services listed, with 3 of these in one location (Washington D.C.). Though not meant to be conclusive, it is probably a good indication of what one would find in a comprehensive search of the largest 20 or 30 cities in the country.

There are no exact figures available, but estimates for the number of deaf people range from 350,000 to 2 million, with major concentrations of deaf persons on the East and West coasts.

The significant number of medical facilities with TTY capability is a direct result of Title V of the Rehabilitation Act of 1973, Section 504(PL 93-112), a federal law passed in 1973,
which provides for legal protection of the rights of deaf individuals. Pertaining to health services, this requires hospitals and other health services that get federal funds to provide emergency TDD numbers and qualified interpreters. New regulations just enacted will expand this to include any business receiving federal assistance.

Performing an exam on a deaf patient requires some modification to the typical exam sequence, but all of the necessary changes are relatively easy. In any situation where the patient's vision will be restricted or blocked, the lighting decreased, or vision fogged, the test explanation and instruction set needs to be given prior to the actual testing. As these guidelines encompass almost every test normally performed in an optometric exam, essentially every test will need to be explained prior to its administration. In addition, once positioned in the instrument, further instructions or reminders are difficult, so fields testing will usually require more breaks so that the instructions can be repeated. An advantage of an interpreter is that in some cases it allows the patient to respond during the test. This can be very important for some tests where impressions or descriptions are needed rather than simple yes or no, or other than two option responses.

The use of an interpreter will usually provide for the most effective, efficient means of doctor-patient communication. While it is the contention of this paper that the use of an impartial, professional interpreter is the preferred method of choice, some patients will be more comfortable with one of the other methods,
whether lipreading, writing notes, or a combination of the two. Some individuals will ask family members or friends to act as interpreters. In these situations explain clearly that the interpreter is not to edit the patient's responses or questions, but to let the practitioner decide the relevancy of the patient's remarks. Understanding the limitations and advantages of each method, as well as the needs of the particular patient, will result in an improved level of care to the deaf population. It should be a priority for the optometrist to become familiar with the unique challenges that a deaf patient represents. Depending on their interest, the optometrist can learn how to properly care for the deaf patient and incorporate those skills into their practice, or, as with other specialties, know who they can refer to. Finally, whether personally involved or not, the optometrist can let the deaf community know that the profession is concerned for their visual welfare by actively working to make quality optometric care more accessible to them.
### NUMBER OF HEALTH CARE FACILITIES WITH TDD CAPABILITY BY STATE

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**Compiled from the 1989 International Telephone Directory for TDD Users**

**Telecommunications for the Deaf Inc. 1989**

**Table One**
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