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Alice Nemon

Department of Counseling, School of Education, San Francisco State University

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DEAF PERSONS AND THEIR DOCTORS

Alice Nemon, M.S.W.

Introduction

Central to the problem of deafness is a handicap in communication which pervades the entire fabric of life for deaf persons. Health is a concern for all people, and one of the major ways to mitigate this concern is the doctor-patient relationship, which depends heavily upon communication.

The effectiveness of communication between healer and patient may strongly influence the course of an illness and its treatment. Impediments to mutual understanding may exist in the form of differences in vocabulary, intelligence, social position, education, the type and amount of medical information possessed by the patient, as well as by the patient's own communication network (Bloom, 1965; Blum, 1960; Glazer, 1970).

Communication is vital to the process of "organizing" an illness. Initially, the patient, seeking a name for the illness, proposes various causes until doctor and patient reach agreement (Balint, 1957). This is necessary in order to proceed to the organized phase of treatment. Communication and the relationship between doctor and patient during this process can be problematic under "normal" conditions, and may be especially complicated between doctors and deaf people disabled in the area of oral communication.

Most doctors see very few deaf patients. Doctors generally have had little or no training in how to communicate with deaf persons and are unfamiliar with American Sign Language syntax. If English syntax is

not used in written communications, the doctor may misunderstand and view this as a reflection of limitations in the deaf patient's intellectual capacity. This may affect the amount of credence given to the deaf patient's reports and questions and the extent to which explanations are given to the deaf patient.

To explore the perceptions and characteristics of the relationship between deaf persons and their doctors, the following exploratory study was conducted.

Sample and Methodology

Twenty-eight hearing-impaired persons were interviewed, including twenty pre-lingually deaf, five adventitiously deaf, and three hard of hearing persons. Also interviewed were three physicians, three interpreters, two dentists, one hearing spouse, one hearing child, and eight professionals who work with deaf people. Many informants were recommended by other informants, with no attempt at random selection. Many were selected because they were available for interviewing, thus not narrowing the sample to people with special medical problems. Questions guiding the interviews centered around health care experiences and concerns, and were open-ended. Interviews with deaf informants were conducted using simultaneous speech and signing. Sixteen of the deaf informants were college graduates, well above the educational norm for the deaf population.

Ms. Nemon is in the Department of Counseling, School of Education, San Francisco State University, San Francisco, California.

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Findings

The more educated and those with the best English language skills were well aware of their advantaged position in the deaf community and felt that those with less English language facility had much greater difficulty with medical care. The advantage was a relative one, as they too had problems.

The primary theme was, predictably, communication. In the health-care encounter the hard of hearing person relied upon hearing and speech most of the time. The adventitiously deaf person with comparatively good speech spoke to the doctor, but felt that some writing of instructions by the doctor was necessary. Almost all informants with good English language skills, except for those few with good speech, brought written prepared lists of symptoms and questions to save time and to prevent misunderstandings. Most preferred that the doctor write answers and instructions. Two of the three informants with lesser English language facility did not bring lists but did use writing to communicate with the doctor. Persons with minimal English language skills are frequently embarrassed at having to reveal their written English language inadequacies.

Satisfaction and dissatisfaction usually centered upon sufficiency of information received. Those informants who had many health problems, but felt that they received sufficient information, felt greater satisfaction and less worry than those who felt they received insufficient information. Unlike hearing people, whose usual reason for changing doctors is that they feel their medical condition is not improving (Suchman, 1972), these deaf informants cited as their primary reason for changing doctors a deficiency in the doctor-patient relationship.

Nearly all commented on the importance of patience in their doctors, a quality difficult to find. Many who had a regular physician said they had tried different doctors until they found one who was patient and did not make them feel rushed; then they remained with that doctor.

The ten informants, all age fifty and over, had regular physicians. They expressed great-

er satisfaction with health care than did younger informants. Eight people, ranging in age from twenty-five to fifty, did not have a regular physician. This group included the two persons in the sample with only a tenth-grade education. While the numbers are small, this may lead to a tentative speculation that lack of education and accompanying limitations may be related to lack of continuity of care.

Because of the importance of written communication, doctors' handwriting was cited as an issue, several informants having changed doctors due to impatient scribbling. Moustaches and 'tight' lips which impede speechreading were not preferred. Many felt that their questions were not fully or clearly answered. Several sought doctors who were willing to explain complicated medical terminology in simple language. A few felt that doctors did not take sufficiently full medical histories, did not explore vague complaints, and did not examine thoroughly. They wondered if this was because the doctor wanted to be finished quickly with them because they were deaf. Several felt discounted and disbelieved, and a few said they felt they were treated as if they were children. Many said that reassurances and medications were given with insufficient information and explanation. A common theme was: "The doctor just does not want to bother." Many wondered, and a few asked, if hearing people were treated similarly.

A few personal experiences were described in which the informants felt that the fact of the patient's deafness led to problems in correctly diagnosing other medical conditions.

One informant felt that misconceptions about deafness can lead to misdiagnosis. His wife had fallen and hurt her hip. A hearing co-worker accompanied her to the hospital and acted as interpreter. When the doctor touched her hip and she screamed, the doctor said that this did not necessarily mean anything as deaf people cannot monitor their voices. The interpreter insisted that such a scream meant pain. The patient stated that she felt the doctor had been minimizing the

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problem. She thought that until he understood that her reaction had nothing to do with how well deaf people monitor their voices, the doctor had not intended to order an X-ray. An X-ray showed a fractured hip and bone cancer.

One may hypothesize that the above concerns, which center upon uncertainty about being understood, problems in communication, and the nearly universally expressed frustration about receiving insufficient information, were particularly disturbing because the patient is left in an unclear position regarding the naming and organizing of the illness. In addition to the extra time required to give full explanations to a deaf person, other factors may be involved. Two factors are "shock-withdrawal-paralysis" (Schlesinger and Meadow, 1972) on the part of doctors and pretending to understand on the part of patients.

Shock-Withdrawal-Paralysis and Pretending

Deafness is invisible. When the hearing person's normal expectations as to how communication should take place are not met, the hearing person may feel disturbed, irritated, frustrated, embarrassed, and inadequate, desiring to terminate the contact quickly (Garrett and Levine, 1962). Schlesinger and Meadow (1972) use the term "shock-withdrawal-paralysis" to describe a phenomenon they have observed in which professionals competent to deal with other problems and handicaps seem to lose their competence when dealing with deaf persons. An already difficult communication is further impeded by negative feelings and attitudes.

The writer witnessed an interchange between an eighteen-year-old deaf woman and her doctor which illustrates shock-withdrawal-paralysis. The woman had had an unsuccessful kidney transplant and had been hospitalized for several months with complicated medical problems. She had recently begun dialysis. Her doctor and a group of residents entered the room and discussed her case. After the residents left, the doctor remained to tell her that she would be having dialysis the next morning. She looked at him un-

comprehendingly. He then hastily wrote something on her pad, almost upside down and quite illegibly. She shook her head. He scribbled again, seeming to retreat as he wrote. Finally, on the fourth attempt he wrote clearly that she would have dialysis the next morning. She nodded and he left. It seemed that much time was wasted because he was uncomfortable and anxious to escape the situation.

Some deaf people pretend comprehension of what hearing people say, partially to avoid uncomfortable interactions.

Two informants told a horror story of a young woman who died as a result of pretending to understand when asked about a penicillin allergy. Seven people were asked about pretending. All knew of it. Two felt the behavior might be taught by one child to another as a way to avoid angering hearing parents and teachers. Pretending was usually seen as a spontaneously developed way for children with minimal language skills to hide their deficiencies and as their defense against accompanying feelings of inadequacy. Pretending helps one to pass.

Residential School Life and Other Early Life Experiences

Another factor seen as influencing health care in adult life is the number of years spent in residential school. This was seen as leading to dependency upon others to take responsibility for most matters, including health care. Issues related to health did not emerge as an important facet of residential school life. Several mentioned fearing visits to the school doctor and nurse, hating shots, and not knowing what was happening to them when they were sick. If they were sick at home, hearing parents would speak with the doctor and the deaf child would not understand what was discussed. This may relate to their present feeling of receiving insufficient information and not knowing what is happening.

One woman had developed as a child many uncorrected, idiosyncratic ideas as to the cause of illness. As an adult, she still experiences the drawing of blood for tests as a dangerous loss. She attributed a recent

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miscarriage to her frequent proximity to a vibrating printing press. Her hearing husband said that she was "like someone from an isolated tribe" in her current limited information and ideas about health.

Confidentiality and Privacy

Confidentiality and privacy emerged as important areas of concern for some informants. Many of the informants deplored the gossip which they felt was very common in the deaf community. The deaf subculture is a linguistic community with frequent social interaction. Set off from the rest of the community by communication barriers, it is to be expected that such a community would have a strong grapevine (Meadow, 1972). Also, because of the public nature of sign language, privacy and confidentiality are difficult to achieve/maintain in a deaf community.

Concern about privacy and confidentiality were particularly prevalent in the area of emotional and family problems. The possibility of being seen in a mental health clinic waiting room and of having one's business spread around was mentioned by a few informants. Schlesinger and Meadow (1972) report that it is not uncommon for deaf patients to ask about other deaf patients in a mental-health encounter. About one-third of the informants obtained doctors' names from deaf friends.

A few of the informants who felt that they could rely upon written communication with confidence expressed some reluctance to involve interpreters. This reluctance was particularly pronounced in areas of emotional problems. Although certified interpreters have been professionally trained to maintain confidentiality, many interpreters are known in and are part of the deaf community, and some informants were reluctant to involve them because of lack of privacy.

Although some informants in particular emphasized privacy and confidentiality as important to them, the different cultural norms in this area may also present some confusion to them. This confusion is illustrated by a deaf college-educated professional woman. She said:

Once in the doctor's waiting room I told my daughter to ask the other people why they were there. I wanted some reassurance that he was a good doctor and had helped them. My daughter said it was not polite to ask them, so we didn't.

Impressions of Doctors, Interpreters and Other Professionals

Three doctors were interviewed, each of whom had from three to ten deaf patients. Two said their deaf patients questioned medical recommendations less than did hearing patients. One doctor saw deaf persons as more stoical about their illnesses, and another felt they seemed especially grateful for whatever was done for them. These doctors did not mind the small amount of extra time which they found was needed by their deaf patients.

Most professionals noted the great difficulty for many deaf persons in making their way through the medical maze. Many are poor and depend upon public-supported facilities. Lack of follow-through on recommendations and missed appointments are frequently due to insufficient understanding. It can make a difference if someone in the medical setting can be enlisted to take an interest in the patient and can help the patient to make his or her way through the system.

The three interpreters interviewed were usually called upon to interpret for persons with minimal English language skills or in which special problems had arisen. Interpreters are trained to facilitate the doctor-patient relationship by positioning themselves as much as possible next to the doctor, facing the patient, so that the doctor and patient will be facing each other (Quigley, 1965). Everything is interpreted, although often in simplified form for persons who would not otherwise understand. The interpreters said they sometimes experience initial resistance from doctors who are not used to outside helpers.

Hearing Children

Children are often called upon to interpret for deaf parents. There are two types of situations in which this occurs: Where the parent is the patient and where the child is

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the patient. In serious medical situations in which the parent is the patient, the children are frequently upset. It is difficult for a child to convey needed information which is beyond his or her comprehension, particularly when the child is under emotional stress.

In one situation, a fifteen-year-old daughter acting as interpreter for her parents was required to tell her mother that she had cancer. The parents had been unprepared for the diagnosis and felt they should have been told to bring a different interpreter to have spared the daughter this very distressing experience.

In some situations, the child may edit what the parent says. This may be to "nicen" the communication in order to avoid embarrassment if the parent's statement was an angry one.

If the child is the patient, one reason for editing what the doctor says is to reduce pressures on the child. The consequences of editing in the mental-health encounter are

especially serious. This kind of early responsibility and power can be difficult for hearing children and for their deaf parents.

Conclusion

Factors contributing to the relationships between deaf patients and their doctors have been discussed. The medical profession is becoming increasingly aware of the need for all patients to participate in their treatment. Recognition is given to the importance of treating the patient with respect, giving credence to what the patient says, and involving the patient actively in his or her treatment. Meeting these goals depends upon successful communication. Doctors need information about and awareness of deaf people's needs and the importance of full and reciprocal communication. Improved communication would result in improved medical care which deaf patients need no less than do hearing patients.

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