

IMPROVING PATIENT CARE

Communicating about Health Care: Observations from Persons Who Are Deaf or Hard of Hearing

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Background: Achieving patient-centered care requires effective communication between physicians and patients. Persons who are deaf or hard of hearing face considerable barriers to communicating with physicians.

Objective: To understand perceptions of health care experiences and suggestions for improving care among deaf or hard-of-hearing individuals.

Design: 4 semistructured group interviews, 2 conducted in American Sign Language (for deaf individuals) and 2 using Communication Access Realtime Translation (for hard-of-hearing individuals). Men and women were interviewed separately. Tapes of interviews were transcribed verbatim for analysis.

Setting: Greater Boston, Massachusetts, and Washington, DC, in 2001.

Participants: 14 deaf adults (23 to 51 years of age) and 12 hard-of-hearing adults (30 to 74 years of age).

Measurements: Commonly expressed themes or views organized around dimensions of communication.

Results: Concerns coalesced around 6 broad themes: conflicting views between physicians and patients about being deaf or hard of hearing; different perceptions about what constitutes effective communication (such as lip reading, writing notes, and sign language interpreter); medication safety and other risks posed by inadequate communication; communication problems during physical examinations and procedures; difficulties interacting with office staff, including in waiting rooms; and problems with telephone communication, such as lengthy message menus. Participants offered extensive suggestions for improvements, starting with clinicians' asking patients about their preferred communication approach. Having patients repeat critical health information (such as medication instructions) can identify potentially dangerous miscommunication.

Conclusions: As the population ages, physicians will encounter many more persons with hearing limitations. Physicians are not reimbursed for making some accommodations, such as hiring sign language interpreters. However, ensuring effective communication is essential to safe, timely, efficient, and patient-centered care.

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Patient-centeredness—respect for and responsiveness to patients' preferences, needs, and values—must guide fundamental health care reform (1, 2). This laudable goal poses particular challenges for certain patient populations. Achieving patient-centered care requires complete and effective communication between clinicians and patients. Today, however, communication between clinicians and many persons who are deaf or hard of hearing falls far from this ideal.

A growing literature—commentaries (3–8) and small surveys of patients (9–11) or clinicians (12–14)—compellingly documents important difficulties confronting persons who are deaf or hard of hearing. Medicare beneficiaries with impaired hearing report lower satisfaction with health care quality and access than do others (15, 16). Some deaf persons have fewer physician visits or mammograms than hearing individuals, although these differences vary by age at onset of deafness (17). In one study involving 14 elderly individuals who have been deaf since early childhood, interviewees reported many practical barriers to communicating with clinicians and office staff (18). Another study interviewed 54 deaf adults about mental health services; interviewees described communication difficulties posing major impediments to mental health care (19). We used group interviews (20–23) to gather detailed informa-

tion from 26 persons who are deaf or hard of hearing about their health care experiences, as well as suggestions for improving care.

METHODS

This study occurred within a larger project examining health care experiences of adults with disabling conditions, using quantitative (15, 16, 24–26) and qualitative research techniques.

Moderator's Guide

From our quantitative findings and literature reviews, we designed an interview addressing 8 topics: overall health care quality, access to primary care, access to specialized services, communication, accessibility experiences in physicians' offices, training physicians about disability accommodations, suggestions for designing accessible health care settings, and disseminating our results among persons with disabilities.

To refine our interview procedures, we consulted an independent living center in Boston, Massachusetts, that targets the Deaf community. We also conducted 2 key informant interviews (23) with a physician–researcher experienced in caring for deaf persons and a hearing American Sign Language expert. To pilot test the draft guide, we

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Context

Few studies describe communication between physicians and deaf or hard-of-hearing people.

Contribution

This qualitative study of 26 people who were deaf or hard of hearing suggests that patients and physicians may have varying views about what it means to be deaf and about effective communication modalities. It also identifies several consequences of inadequate communication with deaf and hard-of-hearing patients, including embarrassment, discomfort, fear, misdiagnosis, and medication errors.

Cautions

This small study conducted in 2 urban sites may not be generalizable to other deaf and hard-of-hearing patients and to different settings.

—The Editors

interviewed a skilled moderator who is deaf and uses sign language; she moderated the group interviews for deaf participants. The moderator's guide is available upon request.

Constituting and Conducting the Group Interviews

We conducted separate group interviews for men and women, convening 2 groups for deaf sign language users in Boston, Massachusetts (10 February 2001), and 2 groups for hard-of-hearing individuals in Washington, DC (15 and 16 May 2001). To recruit participants, we worked with the Boston independent living center and a hard-of-hearing advocacy group.

The moderator and deaf interviewees communicated entirely in sign language without interruption, while 2 skilled interpreters simultaneously spoke their interpretation for researchers seated outside the group. Two video cameras recorded the proceedings, one taping interviewees and another recording the moderator. A hearing researcher moderated the interviews with hard-of-hearing respondents. To facilitate participation, we used assistive listening devices with microphones and simultaneous Communication Access Realtime Translation (27): An expert typed the proceedings using a court stenography machine, while computers translated this phonetic output real-time into English displayed on screens.

The Committee on Clinical Investigations at Beth Israel Deaconess Medical Center approved this study, and participants gave written informed consent. Interviews lasted roughly 2 hours; participants received \$75 at the conclusion. All names provided are pseudonyms.

Analysis

Interview audiotapes were transcribed verbatim. After reviewing transcripts, 2 researchers generated coding categories to facilitate analysis (available upon request). Using these categories, a researcher sorted the texts with NVivo software (QRS International, Melbourne, Australia). These

3 investigators independently analyzed the sorted texts and noted patterns about perceptions of health care (28, 29). We reached consensus during telephone discussions. Another author independently read the transcripts, confirming the validity of preliminary conclusions.

RESULTS

Table 1 presents demographic information about the 26 interviewees. They identified several difficulties, particularly limited insurance coverage for hearing aids, audiology services, and prescription drugs. Most concerns, however, related to communication. Although interviewees described positive experiences, especially with their long-term physicians, most comments underscored problems, which are grouped broadly into 6 themes. Interviewees also suggested potential solutions (Table 2).

Conflicting Assumptions about Deafness

Interviewees felt that most physicians, largely unconsciously, hold fundamental assumptions about deafness that, from the outset, undermine patient-physician relationships. In particular, physicians do not fully appreciate the totality of patients' lives and health concerns. Deaf and hard-of-hearing interviewees reported different perspectives on this theme.

Deaf interviewees suggested that some physicians do not adequately respect patients' intelligence, motivation, and desire to understand and participate in their health care. As John reported:

When I was in hospital [for Guillain-Barré syndrome], 4 or 5 doctors would circle around my bed and talk about me. I didn't know what anybody was saying. They were touching me, they were checking me, they

Table 1. Characteristics of Interviewees by Focus Group*

Characteristic	Deaf		Hard of Hearing	
	Women	Men	Women	Men
Total interviewees, <i>n</i>	8	6	6	6
Age range, <i>y</i>	26–50	23–51	35–65	30–74
Age < 45 <i>y</i> , <i>n</i>	7	3	2	3
Age ≥ 65 <i>y</i> , <i>n</i>	0	0	1	2
White (not Hispanic), <i>n</i>	6	5	6	5
Nonwhite or Hispanic, <i>n</i>	2	1	0	1
Deaf since birth, <i>n</i> †	4	5	NA	NA
Uses hearing aid, <i>n</i> ‡	5	1	6	6
Employed, <i>n</i>	6	6	5	2
Completed high school, <i>n</i>	7	6	6	6
Postbaccalaureate degree, <i>n</i>	0	1	4	0
Annual income < \$20 000, <i>n</i> §	2	0	0	1
Has primary care physician, <i>n</i>	6	5	4	4
Has health insurance, <i>n</i>	8	6	6	5

* NA = not applicable.

† One woman did not answer the question about onset of deafness; all deaf interviewees, not born deaf, were deaf by early childhood.

‡ All deaf interviewees only use hearing aids in selected situations.

§ Two hard-of-hearing women and one man declined to answer the income question.

|| One deaf woman did not answer the question.

Table 2. Interviewees' Suggestions for Improving Communication**Basic training and procedures**

- Train all office staff, including clinicians, about the need to ensure effective communication; discuss professional, ethical, and legal obligations.
- Specialized facilities, such as surgery units, recovery rooms, emergency departments, and radiology suites, should establish specific protocols for effective communication during all phases of care; review policies about removing and returning hearing aids.
- Place prominently in medical record information about patient's desired communication strategy and other related personal preferences.
- Prepare easy-to-read written instructions about what to do before clinician arrives (e.g., which clothes to remove and why).
- Prepare easy-to-read written instructions about examining room or testing procedures.
- Prepare pictures or diagrams depicting tests or procedures; have books with relevant pictures available for more detailed discussions (such as surgery).

Physical environment, resources, and equipment

- Ensure that physical environment meets basic safety standards (such as light signal for fire emergency).
- Use good lighting; clinician (and sign language interpreter) well lit.
- Minimize background noise.
- Learn about local resources, especially sign language interpreter services specifically trained for medical encounters and telephone relay services.
- Acquire and learn how to use teletypewriter (TTY) or telecommunications device for the deaf (TDD) equipment; if unavailable, ensure familiarity with telephone relay services.
- Consider purchasing audio sound system for office communication with persons who are hard of hearing (especially in large practice with elderly patients).
- Review automated telephone menu systems, considering alternatives for persons with hearing loss (e.g., e-mail or fax).
- In radiology units, install colored lights to signal when patient must take certain actions (e.g., holding breath and resuming normal breathing).
- In waiting room, use vibrating pager or other nonvisual, nonauditory means to inform patients when clinician is ready for appointment.

Interactions with patients

- Ask patients about preferred communication approach.
- Make appropriate effort to adhere to patients' preferred communication approach.
- While communicating, always look and speak directly to patients rather than at sign language interpreter, family member, or other person.
- For established patients, plan ahead to ensure required accommodation (e.g., the interpreter) is present for appointment; stay on schedule so interpreters do not leave before visit finishes.
- Ensure that office staff communicates discreetly with patients in public setting (e.g., do not raise voice).
- Introduce all persons who enter room to patients.
- Describe all planned physical maneuvers, and inform patients immediately before touching.
- Periodically ask patients about effectiveness of communication; request suggestions to rectify unsatisfactory situations.
- Periodically ask patients to summarize their understanding to identify miscommunications.
- Provide brief, easy-to-read, written instructions about what to do after encounter.

were talking about me, and I was lying there. Hearing people could at least hear what is going on and maybe have something to say about it, but not me. They come in, treat me like some object in a zoo, and leave.

Interviewees thought that physicians do not comprehend the richness of Deaf cultural and linguistic identities. In particular, physicians seem unaware that American Sign Language has grammar and syntax different from English.

Some interviewees learned English as a second language; they believed that physicians view them as "stupid" when they use faulty English. Respondents wondered why physicians repeatedly question them about what caused their deafness when hearing is irrelevant to their current health concerns. "The medical community holds a pathologic view of deaf people," observed Faith. "They don't see us as a linguistic minority. . . . I don't identify myself as disabled. There's a certain kind of pity on us as deaf people."

Most deaf respondents proudly noted their cultural affiliation and frustration when asked to make communication concessions. "I deal with the hearing world every single day, 24/7," asserted Faith. "I'm tired of writing notes and making do. . . . Could hearing people imagine having to write down all their communication events, all day, every day?"

In contrast, hard-of-hearing respondents did not share a cultural identity. Several admitted that they themselves are ashamed, frustrated with, depressed, or "in denial" about progressively impaired hearing. According to Eric:

When you wake up one day and you don't hear the refrigerator hum or you don't hear paper rustle, it's scary. You want to deny it, say it's temporary, just a head cold, you'll hear better later. But you don't. . . . People just don't understand what it's like.

Nevertheless, hard-of-hearing respondents also felt marginalized by physicians. Their own conflicting attitudes, however, sometimes impeded them from confronting physicians about communication problems. "I don't hear in some situations, and I tend to withdraw, lose confidence, feel isolated," said Patricia. "I wish medical personnel would take hearing loss more seriously. . . . To them hearing loss is easy to deal with. . . . They just talk louder at you. They don't truly have sensitivity or compassion for it."

Conflicting Perceptions of Communication Modalities

Both deaf and hard-of-hearing interviewees reported that physicians frequently require them to use inadequate modes of communication, such as reading lips, writing notes, or bringing family members to interpret. Physicians did not understand their responsibility to ensure effective communication and sometimes complained about costs or inconveniences of hiring interpreters or purchasing special equipment.

When hiring interpreters, physicians often do not seek persons trained specifically in medical sign language. Some clinicians inappropriately maintain eye contact with the interpreter rather than the patient. Sometimes deaf persons have *no* way to communicate. Several deaf respondents described visiting emergency departments for acute problems (such as severe abdominal pain, arm injury, or new-onset Guillain-Barré syndrome) that prevented them from signing. Without interpreters, patients were unaware of crucial

information, precipitating emotions from frustration to terror. "I was freaking out without an interpreter," recounted John, who had known nothing about Guillain-Barré. "I went to the ICU [intensive care unit], and they didn't get an interpreter for 3 days."

Deaf and hard-of-hearing respondents noted difficulties understanding words when lip reading, especially when physicians speak quickly, turn away, bow heads, have foreign accents, or wear beards or masks. Some interviewees would rather write notes than read lips "because you don't want to miss anything. Many words look the same on the mouth." However, physicians sometimes write "\$100 words" that make patients "feel stupid" and afraid to ask questions.

Interviewees acknowledged that disagreements with physicians about optimal communication often revolved around time. Interviewees sought more time than clinicians could or would give. Akysa, who is deaf, recounted an excellent experience when her physician hired an interpreter and took extra time:

Once we got into the doctor's office, we did introductions, and communication was at the right pace. It was wonderful. I signed whatever I wanted to say, and if the interpreter was confused by medical terms, she stopped me, and I wrote down the medical thing. So often it's "hurry up, get in, and get out." This doctor took the time to explain everything to me, and I was pleasantly amazed.

Hard-of-hearing respondents reported that physicians would not speak more slowly even to facilitate communication. "Because we're hard of hearing, the first thing we want is to slow things down," said George. "But the doctor tends to go through a checklist real fast."

Inadequate Communication Has Consequences

For both groups of respondents, inadequate communication can produce negative outcomes. Interviewees noted inhabiting a netherworld between their perceptions of speech and the actual content of speech, as for Denise:

Hard-of-hearing people often think we hear things that are very different from what was actually said. We have no way of checking that. . . . You're concentrating to hear what you think the doctor's going to say, but if you don't hear the questions right, then you can't answer them right. Doctors could come up with a different diagnosis if you answer questions wrong. . . . That happens to us all day long. We're constantly negotiating what we're going to make an issue about hearing and what we're going to ignore.

While acknowledging their responsibilities for miscommunication, interviewees nevertheless felt, "It's the medical professional's responsibility to make sure that patients understand necessary information. We might have

fewer medical mistakes. Some of us have serious consequences." Interviewees described not understanding therapeutic regimens, medication dosages, or side effects. When writing notes to communicate, especially, interviewees believe they get incomplete information. They suggested that physicians should routinely ask patients to repeat instructions to confirm understanding.

Inadequate communication can embarrass patients. "You write back and forth," recalled John, "and the doctor wrote 'C-O-K-E.' I said, 'Yes, a lot.' Suddenly, there were 3 people trailing me to the bathroom for a urine test. I thought they were trying to keep me from running away! I didn't understand where that was coming from. I thought he meant do I drink Coca-Cola. Why didn't he write the whole word 'cocaine'? It's not just 'coke.'"

Communication during Physical Examinations and Procedures

Both deaf and hard-of-hearing interviewees described discomfort and fear when they cannot see clinicians or technicians during physical examinations or procedures. As for several other women, Faith's first Papanicolaou (Pap) smear was "awful":

They didn't tell me what they were going to do. There I was in the stirrups—I couldn't see what was going on. The doctor didn't say to me, "This might be uncomfortable," or tell me how much pain to expect. I never went again.

Men also described difficulties, such as Harry's first testicular examination:

I was scared. I didn't know if I was being molested or raped or if this was a sexual advance. . . . A hearing doctor with a hearing patient will talk through the entire exam, but when the patient is deaf, they just do it. Some doctors keep on talking. They forget I'm deaf.

Men and women reported problems during radiology tests when technicians disappear behind protective screens without adequately instructing patients. "I didn't know I was supposed to hold my breath during the x-ray," said Lois, who needed to repeat her mammogram. "If a person can't hear," asked Sandra, "how do they know when to hold their breath? You can't see the technician." Interviewees suggested using lights as signals for required actions.

Interviewees described important concerns around major operative procedures. One deaf man lay prone, unaware that the physician was about to incise a cyst on his buttock: "They patted me on the shoulder and gave me the thumbs up. Why couldn't they show me the knife and say, 'I'm about to cut'? They did 2 cuts, and I wanted to scream. I didn't know what that was for!" Denise, who is hard of hearing, recalled:

They made me leave my hearing aids with my mother. Afterwards, they told me, "You took a long time to come out of anesthesia. We kept talking to you." But I couldn't hear them! There was no way for me to understand what was going on and get pulled out of anesthesia. It's very scary.

Patients sometimes make their own accommodations. George's wife is also hard of hearing:

When my wife had a baby, she had a C-section. I was in the room with her. The doctors were telling us things to do, but they were all wearing masks. So we got her mother to come in there with us. That was how we dealt with communication issues.

Interacting with Office Staff

Many interviewees, deaf and hard of hearing, raised concerns about not hearing when they are called in waiting rooms. Some miss appointments scheduled long before; others do nothing while waiting except watch to be called. Denise described common experiences:

You can't hear the receptionist. You hope you'll know when they call your name. Then you go into another room, and they tell you to take off some of your clothes, all of your clothes, or none of your clothes. If you get that wrong, you're in trouble. Then you don't hear the doctor at the door. They come in, and you don't know whether you've taken the right clothes off. Each thing seems little in itself. But when it all happens one after the other, you feel very anxious.

Akysha teaches office staff simple sign language. "I walk in, I point to my ears, I shake my head no, and they give me that statue face," Akysha described receptionists. "It takes a few minutes, but then they do okay." Faith, however, worried that sometimes techniques for summoning her compromise her privacy: "The way they approach you is not discreet."

Telephone Communication

For both groups, telephone communication is often problematic. Physicians frequently do not have teletypewriters (TTY) or telecommunications devices for the deaf (TDD) or do not use relay services (that is, special operators, available all day, who translate spoken into written words and vice versa).

"Just simple things like calling up and making appointments is a problem," observed Marion, who is hard of hearing. "The clinic switchboard actually says to me, 'We're too busy right now to take a relay call.'"

Respondents described problems when office staff mumble, speak with heavy accents, or talk rapidly. Automated telephone systems (such as for ordering prescription refills, obtaining test results, or leaving messages) pose special difficulties.

"You push a button for this and that," said Patricia. "I

go through 7 or 8 buttons. You have to hear all the instructions. That takes double time for me because I have to keep going back to the previous menu to know what they said. I find the telephone extremely scary."

Marion and other interviewees reported concerns about accurately hearing test results over the telephone. They prefer obtaining written information through relay or teletypewriter. Physicians, however, often resist using relays. As Marion said:

When we're trying to receive some critical information, we want to make sure we get it right. . . . If doctors call you on regular phones and you don't hear it completely, you're not sure you've got everything right, especially if there are numbers. With a relay, you can read accurate numbers, assuming that the relay operator does it right. . . . But doctors don't want to mess with it. They don't know how to do it, and they don't want to learn. As far as they're concerned, it takes too long.

DISCUSSION

Deaf and hard-of-hearing interviewees highlighted communication problems that could compromise several dimensions of health care quality, including patient-centeredness, safety, effectiveness, timeliness, efficiency, and equity (1, 2). Respondents cited risks for medication errors and misdiagnoses, problems during surgery and anesthesia, missed and delayed appointments, and less complete and accurate information than other patients receive. Although details sometimes differed, deaf and hard-of-hearing respondents expressed similar concerns.

Our findings have important limitations. The 26 interviewees do not represent all persons with hearing loss, especially elderly individuals. Despite extensive efforts, we did not enroll equal numbers of men, although men have considerably higher rates of hearing impairments than women (30). Similarly, we enrolled few racial and ethnic minority interviewees; however, white people have higher rates of impaired hearing than black people (30). Hearing loss results from diverse causes (31–33). Timing of hearing loss holds important implications not only for communication but also for health services use (17). However, we did not design our study to examine health care experiences by type of hearing impairment.

Nonetheless, interviewees offered sensible suggestions for improving their health care experiences. Some suggestions involve strategies persons probably use elsewhere in daily life, but bridging communication gaps in health care might prove challenging. Respondents perceived that physicians do not fully recognize the implications of communication barriers and have fundamental misconceptions about effective communication modalities, which are findings confirmed by others (9–14).

In particular, clinicians often believe that note writing and lip reading provide effective communication (4, 5, 9).

However, only 30% to 45% of English sounds are unambiguously visible on lips (3–5). Writing notes also frequently fails. One study found that fewer than 20% of deaf individuals report fluency in written English (34). Furthermore, American Sign Language and English differ, sometimes producing fundamental misunderstandings (3–7). Older persons who are hard of hearing can find note writing difficult because of low vision, arthritis, or fatigue (3). Relying on family members or friends often does not achieve accurate, effective communication and may compromise privacy (3, 5).

These problems parallel those noted by other linguistic minorities (35–37). One important difference might involve physicians' perceptions of patients' intelligence. Few suggest that physicians systematically view other linguistic minorities as less intelligent than English speakers. Deaf persons, however, worry that physicians question their intellects (18). For more than a century, U.S. educators wrongly linked deafness to low intelligence, stoking prejudice and discrimination (38–40).

Compared with other linguistic minorities, persons with hearing loss have stronger legal mandates to accommodations for ensuring effective communication (5). Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990 require providing effective communication unless doing so would cause significant difficulty or expense. Under both laws, patients' preferences should receive primary consideration, but physicians or other providers determine what constitutes effective communication. Some deaf respondents view sign language interpreters as essential to effective communication, especially in sensitive or complex situations. Neither law requires insurers to cover interpreter costs; clinicians cannot charge patients for this expense. Interpreter fees can exceed reimbursements for the visit (41, 42). Nevertheless, legal experts caution physicians against using ineffective communication strategies. Courts have held physicians legally liable for failing to adequately accommodate communication needs, especially when medical injury ensues (42, 43).

Interviewees suggested ways to improve communication, starting with Patricia's request: "Just ask me, 'How can I best communicate with you?'" Today, an estimated 25 million Americans have hearing loss; these numbers will increase with the aging population (33). Providing high-quality health care to this growing population requires concerted attention and careful listening.

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