

Improving Access and Quality of Health Care for Deaf Populations

A Collaborative Project of the Sinai Health System and

Advocate Health Care

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LESSONS LEARNED

Overarching Lesson: It is essential to collaborate with community leaders

The most successful method for engaging Deaf participants in our projects proved to be the establishment of collaborations with local community leaders at Deaf-serving agencies. This was true whether we were recruiting participants for the survey, for health education classes or for gaining participants' acceptance of unfamiliar methodologies used during various projects. This was also true when hospitals introduced new communication technology. Without input from the Deaf community, new technologies may be viewed as a reduction in communication access, rather than an additional option to improve communication access as intended.

It is imperative that all organizations serving Deaf persons be identified at the onset and that time and energy be devoted to establishing connections with these organizations. Specific effort needs to be focused on recruiting from within agencies that serve disadvantaged and minority subpopulations within the Deaf community.

Lessons learned about providing health education to a Deaf population

The Deaf population has been deprived of many of the modes of accessing health education information enjoyed by the general population. For instance, not being able to talk with their parents about family history or expected health behaviors, not being able to access TV and radio as sources of health information, and not always being able to communicate with their health care providers. This results in a deficit of information among some in the Deaf population about the patient role, knowledge of specific health conditions, disease status and treatment options. However, when offered information tailored to their learning modalities, there can be a significant increase in health knowledge. Lessons learned about delivering effective health education to a Deaf population include the following:

1. It takes the buy-in and support of the community to successfully recruit participants and implement health education classes at multiple locations.

2. Whenever possible, health educators should resemble the population they are teaching in terms of deafness, race/ethnicity, sex and age.
3. Health education classes that integrate evidence-based practices for cardiovascular disease prevention and self-management of depression into a linguistically and culturally sensitive model for Deaf persons are effective and well-accepted.
4. Health education DVDs in American Sign Language (ASL) and online sites are effective tools for the provision of cardiovascular disease prevention, depression self-management and patient activation education. The DVDs that we produced used role playing, a diverse group of “actors” to represent the diverse Deaf population and employed lots of graphics to explain the disease management concepts. Evaluation of these tools indicated significant increases in knowledge.
5. A number of barriers to recruitment and retention in all aspects of our programs were identified. They include the following:
 - a. Lack of transportation and child care can be barriers to consistent attendance and to completion of the program. If possible, they should be made available to participants. Note: we were not able to provide these services.
 - b. Location matters. There is no Deaf neighborhood. The Deaf population is integrated throughout the community. In choosing where to hold events and health classes, we found it effective to schedule them at community centers where Deaf services are already being provided; that is, where the Deaf community already has a relationship and a location to which they are comfortable traveling. If using an outside agency to host the classes, that organization should be offered payment for the use of their space.
 - c. Time of day matters. The Deaf population is diverse in terms of employment. Many are occupied during the day with jobs or school. Others are not working or are retired. It is best to offer classes and presentations both during the day and in the evening to accommodate these differences and ensure optimum recruitment of this diverse population.
 - d. The number of sessions matters. A shortened class schedule to increase participation and to assist with securing a location may be optimal. We offered class series that ranged from four to six classes, with each class lasting at least two hours. This lengthy time commitment proved challenging in terms of finding a community location with that extent of availability. It also presented a challenge to the participants in committing to that length of time.

6. There is a stigma associated with depression in the Deaf community, as elsewhere. The stigma made recruitment and retention into the depression self-management classes challenging. The use of words such as “stress management” and “relaxation” have fewer stigmas associated with them and may lead to increased participation for the depression self-management course.

Lessons learned about what providers need to know in order to provide quality health care for Deaf patients

1. Providers have received little training on how to effectively communicate with Deaf patients. Most providers we interviewed stated a strong preference for having an interpreter in their encounters with Deaf patients. Training, when provided, is effective in promoting effective communication and quality care for Deaf patients.
2. The Americans with Disabilities Act requires healthcare providers – in both inpatient and outpatient settings – to take the necessary steps to ensure effective communication with their Deaf patients. Providers need to develop specific policy and protocol and train staff on how to communicate with Deaf patients. Providers need to be familiar with the variety of tools available to facilitate communication with Deaf patients and to assess each patient’s condition effectively.
3. Health care institutions need to ensure that they are accurately and consistently recording patients’ hearing status in the electronic health record. This information, once recorded in one location, needs to be accessible in different locations throughout the health care institution.
4. All modes of communication assistance should be factored into every practice. Interpreters are readily available in the Chicago area for planned visits, if the health institution has appropriate protocols. However, it is often difficult to access immediate communication for acute and emergency visits. Technology is beginning to offer new solutions to the acute and emergent visit.
5. Technology is facilitating an expanding array of options to facilitate communication with Deaf patients. Video Relay Services (VRS) provide a qualified ASL interpreter to assist with phone calls and make phone conversations for Deaf patients easier than ever. Additionally, there are now a variety of Video Remote Interpreting (VRI) services and devices available for use in the medical setting. VRI can bring an interpreter to the medical encounter in a matter of minutes or even seconds, critical time in an emergency visit. However, it is important to be cognizant of the fact that one mode of communication does not fit the needs of all Deaf patients in all settings. For instance, VRI technology is not appropriate for use with a patient who must lay

flat in bed or for a patient with low vision. Providers should be prepared to use the full range of communication assistance available; from qualified sign language interpreters to VRI and VRS to ASL health education materials.

6. Documentation of the method used to communicate with the Deaf patient needs to be routinely and consistently entered in the medical record.
7. While our institutions have made considerable efforts to accommodate our Deaf patients, many health care providers lack familiarity with Deaf individuals and the knowledge necessary to effectively serve them. Providers need to be aware that many Deaf patients do not have the experience to know what is expected of them as a patient. They may not know how to communicate effectively with a health care professional. They may not have knowledge of their family medical history, especially if their parents were hearing and did not sign. This knowledge deficit requires the provider to be more proactive in eliciting information and feedback from the patient than is the norm for the general population.
8. As demonstrated in our survey, an additional concern in serving Deaf patients is their lack of familiarity with medical terminology and basic health information. Therefore, the provider must take extra care to explain medical issues and to elicit feedback to ensure that understanding has been achieved. The development of more Deaf-friendly health education materials would further facilitate the communication of health information to a Deaf patient.
9. Patient visits take longer because they are being interpreted. Therefore, the visit with a Deaf patient should be routinely booked for a longer time slot.

Lessons learned about conducting health knowledge, behavior and health education research with and about a Deaf population

1. Conducting research and health education in a Deaf population is different from performing the same tasks in the general population.
2. Considerable effort is required to ensure that materials and evaluation questions translated from English into ASL are clearly understood by the intended audience. One English language concept can be signed in a number of ways in ASL. We found it important to take the time and effort to develop a gloss and back translation, and to conduct a tool validity trial with bilingual participants. This was done to ensure standard use of ASL language throughout our studies. We also incorporated explanations of medical terminology into our tools, included variations in the phrasing

of questions, and incorporated prompts, each in a standardized manner. Because of the extra effort taken, the end result was solid research.

3. The Deaf population has had little or no experience participating in research. Despite this unfamiliarity, our participants were pleased to be asked to be a part of research and enthusiastically gave of their time. The retention rate associated with our interventions was generally higher than one would experience in research with other hard-to-reach and vulnerable populations.
4. Maintaining confidentiality in the Deaf population can be challenging and needs to be carefully thought out. The Deaf community is a socially cohesive group. Research assistants may know the participants. Trust may be harder to develop because of this cohesion. Steps to assure participants of confidentiality must be explicit.
5. Standardizing survey instruments, administered in a visual manual rather than a written language, proved challenging. Extensive efforts were made to assure that questions were asked consistently across respondents and across sites, so as to minimize bias. However, interviewers needed to be allowed some flexibility in their technique in order to account for the variations in the fluency and signing style of the person being interviewed. The results of our data analysis have led us to believe that despite the extensive efforts expended in standardizing instruments, certain questions were not asked consistently across sites. However, it seems that generally the standardization was successful.
6. Another important lesson concerns the validity of the measures of health-related quality of life instrument (SF-12) when used with a Deaf population. While it will be necessary to undertake additional analyses to further and more completely validate the use of this instrument with a Deaf population, preliminary results suggest that SF-12 scores correlate well with other measures of physical and mental health status.
7. ASL DVDs were employed to collect evaluation data on our programs. In conducting the evaluations, we found it effective to sign the question twice, allowing participants to view the question, think about it and then clarify their answers before recording them.
8. True/false questions proved a difficult concept, as did the excellent/very good/good/fair/poor scale. Instead, we employed five variations of a “smiley face,” which proved easier to understand.
9. Several techniques were used to obtain consent to participate in research projects. It is not sufficient to hand a Deaf person a consent written in English and expect to get “informed consent.” We asked trusted leaders in the Deaf community to gather

together a group where the project was explained in ASL. Then those interested in participating were interviewed privately, one-on-one in ASL to get a written consent. In this way, we could be sure that participants understood what they were signing.

10. Our research work needs to be further tested and replicated.
 - a. Our survey was conducted among our own patients who, by definition, are well connected to health care. The results of the survey therefore cannot be generalized to all Deaf persons. We would like to see the survey replicated within a randomly selected sample of the Deaf population and those results compared to ours. The contribution to knowledge of the unique health-related issues faced by the Deaf community would be well worth the effort.
 - b. Our survey demonstrated a health knowledge deficit among our Deaf patients. We, along with some others in the field, developed health information materials and health education programs aimed specifically at Deaf individuals. These materials and programs need to be evaluated in additional populations to confirm what works best in increasing the health knowledge of Deaf persons.
 - c. Finally, in our survey we used many questions from validated health surveys commonly used in the general population, but which had not previously been used with Deaf respondents. The SF-12 is a prime example. There is much work to do in testing these research instruments for validity and reliability with Deaf persons, so as to enable comparison studies of Deaf and general populations. Research into the development of effective, standardized screening tools for use with a Deaf population is also warranted. These standardized screening tools could then be disseminated to all providers for use with their Deaf patients.

Public policy implications of lessons learned

1. The material resources necessary to provide quality health care services to a Deaf population exceed those needed to provide the same level of care to the general population. For one, a Deaf person's medical encounter takes longer. This is partly a factor of the extra time involved in ASL interpretation. However, even a provider fluent in ASL requires more time with a Deaf patient given the general deficit in health knowledge, a deficit demonstrated by our survey results.
2. The need for an ASL interpreter is an additional cost. The Americans with Disabilities Act requires health care institutions to make "every reasonable effort" to ensure

effective communication with their Deaf patients. Neither Medicare nor Medicaid provides sufficient remuneration to cover these extra costs, putting health care institutions in a difficult spot. There is no additional reimbursement for interpreter time, although some states do include interpreter time in their Medicaid reimbursement. We recommend the exploration of methods of payment for the additional services and time needed to provide quality care to Deaf patients.

3. Since the language of most Deaf persons (ASL) is a visual-manual one, the opportunities for the use of “telemedicine” with this population are intriguing. Funding to test effective uses of these and other technologies is recommended, as well as funding of the purchase of the equipment.
4. Collaboration among healthcare organizations can be an effective way of providing appropriate communication with Deaf patients. Banding together to provide interpreter services can spread the cost over a larger pool, thus reducing costs for the group. Minneapolis-St. Paul hospitals have entered into collaboration and report improved access to interpreter services. The IVIN system used at Sinai Health System and the In-Demand system recently adopted at Advocate sites provide qualified sign language interpreters by VRI with interpreters located in several locations across the country. When one location is busy, it is likely that another will have interpreters available due to time difference. Thus, interpreters are available as needed, quickly and at a cost comparable to or less than face-to-face interpreters.
5. Our research demonstrated the effectiveness of health education materials adapted for use by the Deaf population. Such materials should be more readily available to all providers and more generally available to the Deaf population.
6. These health education materials should be used to develop curriculum for Deaf school children, thus eliminating some of the health education deficit we found in the current adult Deaf population.
7. We found little existing research on the health knowledge of Deaf individuals. We recommend that Deaf individuals be included in national health surveys.
8. It is almost impossible to determine the number of Deaf people in any given geographic area or within any demographic group. While the Census does collect hearing loss status in the randomly collected “long survey,” we recommend that the Census begin to gather data on hearing status in the universally collected short survey.