

DEVELOPING A STANDARDIZED COMPREHENSIVE HEALTH SURVEY FOR USE WITH DEAF ADULTS

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HERE IS LIMITED INFORMATION on how communication barriers impact on the health of deaf individuals. The present article describes the development of a standardized interview tool to collect health-related information from deaf adults via face-to-face interviews in American Sign Language (ASL). Questions were selected largely from existing standardized questionnaires. Key steps in standardizing the instrument included the creation of an ASL gloss version of the survey and extensive interviewer training. The instrument was pilot-tested and revised prior to implementation. There were 139 questions on the final instrument. A total of 203 interviews were conducted between November 2002 and March 2003. A standardized interview survey administered in ASL proved an effective and well-accepted means of collecting health-related information from a diverse sample of deaf individuals. Several challenges were encountered throughout the process, and the resulting lessons will be useful to future research efforts.

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An estimated 28 million people in the United States (approximately 10% of the population) have some degree of hearing loss (Lucas, Schiller, & Benson, 2004), and the prevalence of this disability is increasing as the U.S. population ages. The proportion that self-identify as culturally Deaf is more difficult to define. According to the National Center for Health Statistics, 0.5% of the population ages 3 years and older is profoundly deaf, a figure that may approximate the number who are culturally Deaf (Ries, 1994).

The first language of more than half of all Americans with significant hearing loss and of most culturally Deaf people living in the United States is American Sign Language (ASL). Most deaf people are not bilingual and, therefore, are not fluent in English. Consequently, prelingually deaf persons often have significant problems with

written language (McEwen & Anton-Culver, 1988; Philips, 1996).

The special communication and cultural needs of deaf individuals may lead to significant gaps in their knowledge about health, healthy living, and how to act properly in a patient role within the health care system. The limited English skills of many deaf adults means that they may not be able to fully comprehend the written health information they encounter in their doctor's office, nor the captioning for a health-related program that appears on television. Often, the communication attempts they have made with their health care providers have proven unproductive and frustrating. Most physicians overestimate the percentage of deaf patients who are proficient in English and do not realize the severe limitations of speechreading. The most skilled speechreader correctly inter-

prets only 25% to 30% of the movements he or she detects on a hearing person's lips (Phillips, 1996). Additionally, deaf persons may have limited English reading and writing skills, which can make writing back and forth as a means of communicating with a health professional highly ineffective. Therefore, the only way to ensure effective communication with deaf patients is to speak to them in their native language. Generally, this means health care providers need an ASL interpreter to be present. According to the Americans With Disabilities Act of 1990, all deaf patients who need or request an interpreter should be provided with one. Unfortunately, this is not a right that is always honored.

One would therefore expect that deaf persons' increased risk of developing deficits in their knowledge of health, the elements of healthy living, and the mechanisms of health care systems would affect their overall health status and health behaviors. However, little prior published research has documented whether this is in fact the case. What is available has largely focused on specific health issues (Heutel & Rothstein, 2001; Woodroffe, Gorenflo, Meador, & Zazove, 1998) or has included individuals with varying degrees of hearing loss rather than focus specifically on deaf persons (Lass, Frankin, Bertrand, & Baker, 1978; Tamaskar et al., 2000; Zazove et al., 1993). For this reason, Chicago's two major providers of health and mental health care to deaf persons, Sinai Health System (identified as Site 1 in the present study) and Advocate Health Care (identified as Site 2), collaborated to develop and implement a comprehensive health survey that would be sensitive to the communication and cultural needs of the Deaf community.

Both health systems offer specialized general and mental health care

programs aimed at deaf and hard of hearing persons, with each program serving approximately 500 patients. Sinai Health System primarily serves Chicago's west and south sides, inner-city areas where residents tend to be on the lower end of the socioeconomic spectrum. Conversely, Advocate Health Care primarily serves Chicago's north side and northern suburbs, areas that are home to members of the middle to upper socioeconomic strata.

The goal of the developed survey was to collect information about the health status, health care experiences, communication styles, barriers to health care, health knowledge, and health-related behaviors of a sample of clients from each health care system who were deaf and proficient in ASL. As it was anticipated that several participants would be limited in their English-language skills, it was the project team's goal to develop a tool that would be administered in ASL. Collecting such information is the first step in improving the health status and knowledge of deaf individuals.

The present article describes the process followed in developing a standardized interview tool to collect health-related information from deaf adults. Discussion also focuses on the unique challenges inherent in designing and administering such an instrument in a visual-manual language (i.e., ASL) rather than in a written language.

The Project Team

The project team was composed of individuals from the two collaborating institutions; many of its members had extensive experience working with deaf patients. The team included health care professionals (mental and physical health), researchers, a certified ASL interpreter, and administrators. Some members of the project team were hearing and others were

deaf. The breadth of expertise possessed by the project team members was invaluable in ensuring that the process of designing and administering the survey was well thought out and culturally appropriate.

Developing the Instrument

Given the communication issues inherent in working with a deaf population, and the low level of English proficiency of many of the deaf patients of the two participating health care systems, the project team decided from the beginning that the survey would be administered in ASL in standardized face-to-face interviews. In order to be conducted effectively, each interview would have to be completed in an hour or less. As translation from English to ASL would increase the administration time of the survey, the goal was to design an instrument consisting of no more than 150 questions.

A review of the literature and discussion among project team members identified survey tools that were examined as starting points during instrument development. As little published research has employed survey techniques in documenting the health status, health knowledge, and health-related behaviors of deaf persons, only a few relevant instruments emerged as starting points (MacKinney, Walters, Bird, & Nattinger, 1995; Tamaskar et al., 2000; Zazove et al., 1993). Concepts that had been well researched among the hearing population were found to be unstudied among deaf persons. For example, in recent years the concept of health-related quality of life has been extensively examined among many populations, including the general U.S. population, different racial and ethnic groups, people from different countries, and disease-specific groups. It has been established that people assess their own physical,

mental, and social well-being relatively well. In fact, numerous studies have shown that people's own perceptions of their overall health are remarkably accurate and can be used to predict future health care needs, as well as rates of 5- and 10-year mortality (Idler & Benyamini, 1997; Idler & Ronald, 1990; Idler, Russell, & Davis, 2000; McGee, Liao, Cao, & Cooper, 1999). While several inventories that measure health-related quality of life have been developed and studied with several different populations, the literature review revealed none that had been used with deaf persons. The project team therefore felt it important to include a measure of health-related quality of life on the survey.

The next step was to decide on the specific domains that would be included on the survey. The project team made this decision after much discussion, and in consideration of the findings of the literature review. The four main content domains were:

1. demographics and other general information (e.g., age, income, insurance status, frequency of interaction with hearing individuals)
2. access to and quality of care (e.g., availability and use of interpreters, methods of communication with one's doctor or counselor)
3. health-related knowledge, attitudes, and behavior (e.g., in regard to smoking, heart attack, or HIV)
4. health-related quality of life, as measured by the Medical Outcomes Study Short Form-12, version 2 (Ware Jr., Kosinski, & Keller, 1996)

These four domains and all relevant subtopics included on the final instrument are listed in Table 1.

Table 1
Survey Domains and Subtopics

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|-------------------------------------------------------|
| 1. Demographics and other general information |
| 2. Access to and quality of care |
| 3. Health-related knowledge, attitudes, and behaviors |
| Exercise |
| Nutrition/eating habits |
| Weight status |
| Cancer screening |
| Recognition of medical terminology |
| Cholesterol |
| Blood pressure |
| Cardiovascular disease |
| Alcohol/drugs |
| Smoking |
| HIV/AIDS |
| Mental health |
| Medication use |
| 4. Health-related quality of life |

The next step was to identify specific questions by which to obtain the information of interest. In order to allow for comparisons between the findings of the survey and data on other populations (i.e., the general hearing population of the United States), as many questions as possible were selected from existing standardized or widely used questionnaires such as the National Health Interview Survey (National Center for Health Statistics) and the Behavioral Risk Factor Surveillance System (Centers for Disease Control and Prevention). It is important to point out that this was the first time most of these questions had been used with a deaf population. Once the topics and inventories were assembled, a draft of the interview instrument was constructed, reviewed multiple times over the course of several months, and revised.

The instrument then needed to be translated into ASL. The project team's research assistants (who also served as the interviewers during administration of the survey) were primarily responsible for this task. The research assis-

tants were native signers and active members of the local Deaf community. Collaboratively, they created a gloss for each question on the completed survey instrument. A gloss is a written representation of each question as it is to be translated into ASL—in other words, a script for sign language. It is important to bear in mind that ASL is a visual language and cannot be completely captured in a written format. Nonetheless, use of an ASL gloss was vital, because the gloss would portray the essence of the question to the interviewer. The gloss thus served as a training tool for interviewers, and ensured that questions were asked consistently across subjects and across sites. Creation of the gloss therefore was a vital step in the standardization of the survey instrument. Giving those who would be conducting the interviews responsibility for translating the instrument into ASL was also a key training event, because the research assistants first needed a good understanding of the type of information each question was aiming to capture (in order to create the gloss). When

completed, the gloss was thoroughly reviewed by the other members of the project team proficient in ASL and was revised accordingly.

A comprehensive review of the literature and conversations with others familiar with health-related quality of life research revealed that the Medical Outcomes Study Short Form-12, version 2, had never been used before with a deaf population. Therefore, the translation of the instrument into ASL also included translation of the form.

Training the Interviewers

The project's two research assistants served as the interviewers. Each participated in a formal training session with the project's research coordinator prior to the pilot phase of the study. The purpose of the training was to ensure that all of the data gathered from the survey respondents were collected and recorded consistently. The training session was about 2 hours long and covered seven areas: recruitment, screening, informed consent, interview techniques and rules, an orientation to the survey (e.g., formatting, instructions, skip patterns), recording of responses, and data editing. The interviewers also videotaped each other going through the mock interviews, critiqued one another, and worked collectively to further standardize their approach. Finally, each interviewer went through a mock interview with a project team member for further practice.

Eligibility Criteria for Participants

Participants were recruited from among deaf clients 18 years of age or older seen in a general or mental health clinic of either of the two participating health systems. A person was invited to participate if he or she expressed an interest in doing so and met cer-

tain eligibility criteria. For one, the person had to indicate that he or she was primarily responsible for making personal health decisions. In other words, the person could not reside in a group home or have a legal guardian. In addition, the individual had to be proficient in ASL. In order to be eligible, individuals who did not designate ASL as their primary mode of communication had to indicate that they were prelingually deaf (i.e., had become deaf before the age of 3 years) or that they self-identified with the Deaf community.

Recruitment of Participants

Participants were recruited slightly differently at each institution. Although in both instances they were recruited from among deaf patients seen in either a general or a mental health clinic, recruitment was primarily face to face at Site 1, Sinai Health System. The research assistant screened appointment records for potential participants. When a patient came in for a scheduled appointment, the research assistant would approach, provide a brief personal introduction as well as an introduction of the study (using a standard recruitment script), and would then determine whether the person was potentially interested in participating. If the patient did express interest, then that individual's eligibility for the study would be determined using a standard form. This process worked well at Site 1, as all clients were recruited from one of three clinic sites. The research assistant therefore could easily get to a clinic whenever a deaf patient came in for an appointment.

At Site 2, Advocate Health Care, the clinics where participants were recruited were distributed throughout Chicago and its suburbs, making it unrealistic for recruitment to proceed exclusively through face-to-face contact. Therefore, while some partici-

pants were recruited face to face, more often clients were contacted either by TTY, e-mail, or fax, and an appointment scheduled specifically for an interview. The study was introduced during this initial contact.

The Informed Consent Process

The prior experiences of project team members working with deaf clients and recommendations from other researchers (especially at Gallaudet University) led to the informed consent process being set up with three options: (a) a consent form in English for potential participants to read and sign, (b) a brief video pamphlet translating the English form into ASL, and (c) an ASL version of the form presented to the potential participant by the research assistant. Respondents were asked to choose one of these methods. Regardless of the method selected, the participant had the opportunity to ask the research assistant questions before signing the paper version of the consent form. Interestingly, no one opted for the videotape version of the consent form. Rather, about one third of participants chose the paper version, while two thirds chose to have the research assistant present the form in ASL.

Pilot-Testing the Instrument

Each site tested the recruitment process, informed consent process, and survey instrument with 5 to 10 clients. A total of 14 pilot interviews were conducted, in November and December 2002. The pilot-testing proved to be a useful process that resulted in several changes to the survey. For example:

- Changing the order of the questions so that more sensitive questions (e.g., concerning HIV or alcohol use) were asked toward

the end, after rapport had been established between the interviewer and the respondent.

- Establishing consistent response categories across similar questions.
- Adding a “no coded response applicable” category to certain questions to accommodate answers from respondents that did not always fit into one of the predefined groups.
- Revising questions that were confusing to respondents.
- Replacing ambiguous categories with numeric scales, as it was found that respondents had a hard time placing themselves in categories. For example, the question “How important is getting exercise to you personally? (very important, important, somewhat important, not very important)” was revised to read, “On a scale from 1 to 10, where 1 is ‘not at all important’ and 10 is ‘very important,’ how important is getting exercise to you personally?”
- Using flash cards with numeric scales as visual aids, thereby clearly orienting the respondent toward giving either a negative response (e.g., “not at all important”) or a positive response (e.g., “very important”).
- Changing true/false questions to yes/no questions, as the true/false concept does not translate well into ASL.
- Clarifying interviewer instructions that were not conveying the intended message.

The Final Survey Instrument

The final survey instrument consisted of 139 questions, with interviews generally taking about an hour to complete. Women and people over the age of 50 years had more questions to an-

swer and sometimes took slightly longer. Each participant was given \$50 for completing an interview. A total of 203 interviews of deaf adult patients of one of the two participating health care systems were conducted between November 2002 and March 2003. Interestingly, all who were eligible to participate (85% of those screened) agreed to do so. The resulting survey population was very diverse. As Tables 2 and 3 show, participants recruited from the two sites differed significantly in many of their characteristics. The diversity of

the surveyed population is an asset of the study, and a product of the collaboration between two health systems in collecting the data. However, the diversity of the sample, particularly with regard to communication skills, also proved a challenge in the standardization of the instrument.

Standardization and Reproducibility

It was the project team’s goal to create a standardized instrument that could be adopted by others interested in

Table 2
Demographic Characteristics of Survey Respondents

Characteristic		Site 1 (n = 102)	Site 2 (n = 101)	Total sample (N = 203)	p ^a
Gender	Female	55%	53%	54%	ns
Race/ethnicity	Black (non-Hispanic)	51%	6%	29%	<.0001
	White (non-Hispanic)	29%	82%	56%	
	Hispanic	13%	7%	10%	
	Other	7%	5%	6%	
Age	Mean (years)	44	46	45	ns
Residence	Chicago	86%	30%	58%	<.0001
	Suburbs	14%	70%	42%	
Education level ^b	Did not complete high school	19%	14%	16%	<.0001
	Completed high school	47%	20%	34%	
	Beyond high school	20%	43%	31%	
School type	College graduate	11%	18%	14%	ns
	Residential	33%	34%	34%	
	Mainstream ^c	63%	53%	58%	
Income	Other ^d	4%	13%	8%	<.0001
	≤\$20,000	60%	46%	53%	
	\$20,001–\$40,000	7%	38%	23%	
	>\$40,000	9%	12%	11%	
Employment status	Don't know	24%	4%	14%	<.0001
	Employed	29%	63%	46%	
	Laid off/unemployed	23%	14%	19%	
	Retired	10%	10%	10%	
	Other ^d	39%	12%	26%	

Notes. Site 1, Sinai Health System; Site 2, Advocate Health Care. Because of rounding, not all percentages add up to 100.

^ap value of characteristics between sites. Chi-square/Fisher was used as appropriate to assess significance of categorical variables; t test for continuous variables; ns = not significant (p > .05).

^bSome responses could not be coded and are not presented, so percentages add up to less than 100.

^c“Mainstream” includes schools with and without specialized programs for deaf children.

^dAt Site 1, the most commonly written “other” response was SSI/SSDI (Supplementary Security Income/Social Security Disability Insurance); 21% of Site 1 respondents gave this answer.

Table 3
Survey Respondents' Sources of Health Insurance

	Site 1 (n = 102)	Site 2 (n = 101)	Total sample (N = 203)	p ^a
Medicaid	49%	18%	34%	<.0001
Medicare	43%	15%	29%	<.0001
Employer sponsored	18%	60%	39%	<.0001
Other private source	1%	6%	3%	ns
No insurance	9%	6%	7%	ns

Notes. Respondents could indicate more than one source of insurance. Site 1, Sinai Health System; Site 2, Advocate Health Care.
^ap value of characteristics between sites. Chi-square/Fisher as appropriate was used to assess significance of categorical variables; ns = not significant ($p > .05$).

collecting similar information from deaf populations throughout the United States. As ASL is not a written language, an ASL gloss alone is not sufficient to ensure that others wishing to use the survey will maintain the validity and reliability of the instrument. The survey instrument has therefore been put on videotape in ASL, and is available to others wishing to replicate this effort. The video is not intended to be used directly in administering the survey, but to serve as a means of conveying the essence of each question to the interviewers. As such, it can be used as a training tool for the interviewers, ensuring that they understand the meaning of each question and providing guidance as to how that meaning might be conveyed. The exact method of signing the questions may need to be modified for the sake of appropriateness to the population being interviewed. The extensive training activities documented in the present article are also necessary in ensuring that the validity and reliability of the instrument are maintained. Information on obtaining the video version of the survey instrument is available on two Web sites:

- http://www.sinai.org/deaf_access/index.asp

- <http://zed.rd.imagescape.com:9090/acf/cause/location/immc/deaf.html>

Each Web site also contains a link to the full survey report.

Challenges and Lessons Learned

There are certain unique challenges associated with conducting research with deaf individuals. The extensive experience of several project team members with deaf patients allowed many of these challenges to be anticipated prior to initiation of the project. They were therefore kept under consideration during the planning phase. Other, unanticipated challenges presented themselves later in the process. Throughout, numerous lessons were learned that will be useful in the planning of future research efforts, program development, and service delivery.

Challenges

The greatest challenge involved the standardization of the survey instrument, which was to be administered in a visual-manual language rather than a written language. Extensive efforts were made to ensure that questions were asked consistently across re-

spondents 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 each person being interviewed. One of the main purposes of the extensive training that interviewers underwent prior to initiation of the study was to ensure that they were well aware of the information each question was intended to gather, and as such, to minimize the amount of error introduced into the survey data as a result of the need to accommodate varying communication styles.

Nonetheless, the results of the data analysis suggest that despite these extensive efforts, certain questions were not asked consistently across sites. For example, respondents were asked about the amount of exercise they got in a typical week. A definition of exercise and some examples of activities that would constitute exercise were included as part of the question. The data analysis revealed that respondents at Site 1 reported significantly more days of exercise than respondents at Site 2. At first it seemed that such differences might be explained by the fact that Site 1 respondents were more likely to reside in the city of Chicago (see Table 2), and therefore might rely more on walking as a means of transportation. However, when the data were analyzed by site and by area of residence (i.e., Chicago versus a suburb), the site differences remained. At the completion of the study, the interviewers were debriefed about this question and a few others for which the data revealed unanticipated and unexplainable trends. The results of the debriefing suggest that this question was asked slightly differently by each of the interviewers. Interestingly, however, the true explanation may be in the reason behind the question being asked differently at each site. It

seems that the Site 2 interviewer had to define the term *exercise* for most respondents, while Site 1 respondents generally understood the term. The Site 1 interviewer revealed that several of his interviewees mentioned that their doctor had spoken to them about getting more exercise, and had suggested walking as a means of exercise. Therefore, the site differences may be real, but an understanding of how the question was asked is beneficial in the interpretation of the data. In this respect, the debriefing of the interviewers was an invaluable part of the process.

Overall, there was only concern about 4 of the 139 questions. It therefore seems that the standardization approach was generally successful.

Another challenge concerned the lack of familiarity of most participants with research and research methods. Some of this was anticipated, and the pilot-testing of the survey instrument helped the project team work through certain assumptions about the way data should be collected or the way questions should be asked that might not work well with deaf persons. Some of these issues concerned specific types of questions that did not translate well into ASL (e.g., true/false questions), while others concerned a lack of familiarity among participants with common research questions and categories (e.g., excellent/very good/good/fair/poor).

The fact that a fair number of participants were recruited from mental health clinics further complicated the data collection process. For example, some participants with chronic mental illness lacked basic organizational skills, and therefore missed two or three scheduled appointments before finally completing the interview. It was also a challenge to collect data from some mentally ill participants once

they came in for an interview. For example, respondents with significant levels of anxiety tended to worry about answering questions "correctly," and therefore often surrounded the actual answer to a question with lots of extenuating and unnecessary information. The interviewers, however, had been prepared for how the more seriously mentally ill participants might respond. Also, before undertaking the survey, the project team had decided that people living in group homes and those with legal guardians would be excluded from the study. These exclusion criteria had two purposes: First, they guaranteed that the person being interviewed had direct experience with and knowledge of the health care system. Second, they ensured that people with serious developmental delays or active psychotic features who might not be capable of properly answering the questions would not be included.

Another challenge to data collection had to do with the fact that the survey needed to be conducted in face-to-face interviews. This presented more of a challenge for Site 2, with its many clinic locations. At Site 2, the interviewer had to set up appointments and travel to various sites to conduct the interviews. Also, the fact that the participants were interviewed face to face made it impossible to conduct the survey anonymously. As a result, the credibility of some of the data, particularly around more sensitive topics such as HIV or alcohol use, may have been diminished. Also, questions concerning health care services may not have been answered completely honestly because respondents may have feared that the services they received would be affected by their responses. It is important to note, however, that the consent form specifically stated that responses to survey questions would in no way affect access to services or the quality of

services. In addition, the research assistants administering the survey were members of the Deaf community and sometimes knew a participant personally. Although it was stressed that responses would be kept confidential, it is possible that this affected responses to more sensitive questions.

A final challenge concerns the time required to conduct the interview. It was felt that it would be unrealistic to expect people to participate in an interview much longer than an hour. With a hearing population, 400 to 500 questions could have been asked in that amount of time; however, translation of questions into ASL greatly increases administration time. Consequently, only a limited amount of data could be collected, and it was necessary to prioritize the information that was of most interest. Even an hour seemed like a large time commitment, and there was some concern that this might be a deterrent to some people. However, this concern turned out to be unwarranted. Most respondents were very enthusiastic about participating and were excited about the opportunity to express their opinions. Socialization within a deaf-friendly environment is highly valued within Deaf culture, and this value appears to have extended into an interview situation with a native signer.

Lessons Learned

The general willingness and enthusiasm displayed by deaf patients at each of the participating health care systems probably provided the most positive lesson learned from the research effort for the present study. While the concept of research was new to most of those interviewed, people were overwhelmingly cooperative and eager to tell their stories, express their opinions and frustrations, and provide information that might prove

useful in improving health care for the Deaf community. However, it is important to reiterate that each of the participating institutions has a strong program of services for the deaf and rapport with its patients. It is unclear how well such a survey would be received in the general Deaf community.

Another important lesson related to the feasibility of conducting a standardized survey in ASL with a diverse study population. As Tables 2 and 3 show, in terms of race or ethnicity and socioeconomic status, respondents from the two sites were very different. During the data analysis, particular attention was paid to differences in findings by site to ensure that they were representative of true variation and not related to differences in how questions were asked or understood. In most instances, the site differences were consistent with what would be expected given the differences in socioeconomic status between the two sites. For example, given that the Site 2 participants were generally more educated, it would be expected that they would have higher levels of knowledge. In most cases, this was true. In the few cases in which site differences were not easily explained by socioeconomic status, other explanations emerged during the debriefing of the interviewers. It therefore seems likely that the survey instrument is appropriate for deaf individuals with varying characteristics and backgrounds, provided that the methodology described in the present article is followed.

Finally, several lessons were learned pertaining to the best way to ask questions of deaf individuals. First, it was found that visual aids greatly facilitate the data collection process. In the current survey, flash cards were used with numeric scales in order to orient the respondent toward giving either a negative or a positive response. It was

suggested during the debriefing of the interviewers that it would also have been useful to use visual aids with other questions. For example, respondents were asked how many servings of certain foods they ate in a typical day (e.g., dairy products). It would have been useful to have flash cards with pictures of the types of foods in each category to use with those questions. Another lesson was that numeric scales work better than ambiguous categories with deaf respondents. Respondents tended to have a hard time placing themselves in a category such as “very good” versus “good.” This might be due partly to a lack of familiarity with research and such scales, and partly to the translation of words such as *very* into ASL. Nonetheless, it was fortunate that this nuance was revealed during the pilot phase so that the survey instrument could be adjusted accordingly. Similarly, it was discovered during the pilot phase that the concept of true/false does not translate well into ASL. As a result, questions were revised to ask respondents whether or not they agreed with certain statements (yes or no).

Conclusion

A face-to-face standardized interview survey administered in ASL proved an effective and well-accepted means of collecting health-related information from a diverse sample of deaf individuals. The use of interviewers who were native signers and members of the local Deaf community, along with the rapport that each health care system had with its deaf patients, likely contributed to the survey’s favorable reception. It is unclear how well such a survey would be received in the general Deaf community.

The process of developing, standardizing, and conducting a survey in

a visual-manual language (i.e., in ASL) rather than in a written language is unique and requires considerable effort. Several challenges were encountered throughout the process, and the resulting lessons learned will be useful to future research efforts with the deaf population. Such research efforts are essential to gaining a better understanding of the barriers deaf persons face in interacting with the health care system and in obtaining health-related information, and to understanding more fully how these barriers affect deaf persons’ health status and health-related knowledge and behaviors. Results from such surveys will be constructive in driving the development of effective interventions and policies intended to improve conditions for deaf individuals.

References

- Heuttel, K. L., & Rothstein, W. G. (2001). HIV/AIDS knowledge and information sources among deaf and hard of hearing college students. *American Annals of the Deaf, 146*, 280–86.
- Idler, E. L., & Benyamini, Y. (1997). Self-rated health and mortality: A review of twenty-seven community studies. *Journal of Health and Social Behavior, 38*, 21–37.
- Idler, E. L., & Ronald, J. A. (1990). Self-rated health and mortality in the NHANES I Epidemiologic Follow-up Study. *American Journal of Public Health, 80*, 446–52.
- Idler, E. L., Russell, L. B., & Davis, D. (2000). Survival, functional limitations, and self-rated health in the NHANES I Epidemiologic Follow-up Study, 1992. *American Journal of Epidemiology, 152*, 874–83.
- Lass, L. G., Frankin, R. R., Bertrand, W. E., & Baker, J. (1978). Health knowledge, attitudes, and practices of the deaf population in Greater New Orleans: A pilot study. *American Annals of the Deaf, 123*, 960–67.
- Lucas, J. W., Schiller, J. S., & Benson, V. (2004). Summary of health statistics for U.S. adults: National Health Interview Survey, 2001. *Vital Health Statistics, 10*(218), 1–143.
- MacKinney, T. G., Walters, D., Bird, G., & Nattinger, A. (1995). Improvements in preventive care and communication for deaf patients. *Journal of General Internal Medicine, 10*, 133–37.

- McEwen, E., & Anton-Culver, H. (1988). The medical communication of deaf patients. *Journal of Family Practice, 26*(3), 289-91.
- McGee, D. L., Liao, Y., Cao, G., & Cooper, R. S. (1999). Self-reported health status and mortality in a multiethnic U.S. cohort. *American Journal of Epidemiology, 149*, 41-46.
- Phillips, B. A. (1996). Bringing culture to the forefront: Formulating diagnostic impressions of deaf and hard of hearing people at times of medical crisis. *Professional Psychology: Research and Practice, 27*(2), 137-44.
- Ries, P. W. (1994). Prevalence and characteristics of persons with hearing trouble: United States, 1990-91. *Vital Health Statistics, 10*(188), 1-75.
- Tamaskar, P., Malia, T., Stern, C., Gorenflo, D., Meador, H., & Zazove, P. (2000). Preventive attitudes and beliefs of deaf and hard-of-hearing individuals. *Archives of Family Medicine, 9*, 518-25.
- Ware Jr., H. E., Kosinski, M., & Keller, S. D. (1996). A twelve-item short-form health survey: Construction of scales and preliminary tests of reliability and validity. *Medical Care, 34*(3), 220-23.
- Woodroffe, T., Gorenflo, D. W., Meador, H. E., & Zazove, P. (1998). Knowledge and attitudes about AIDS among deaf and hard of hearing persons. *AIDS Care, 10*, 377-386.
- Zazove, P., Niemann, L. C., Gorenflo, D. W., Carmack, C., Mehr, D., Coyne, J. C., & Antonucci, T. (1993). The health status and health care utilization of deaf and hard-of-hearing persons. *Archives of Family Medicine, 2*, 745-52.