

IMPROVING THE FEASIBILITY OF INCLUDING DEAF RESPONDENTS IN TELEPHONE SURVEYS

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Introduction

Health statistics are frequently collected through telephone surveys. This mode of data collection limits participation of an estimated 10 million deaf and hearing impaired persons¹ unless special efforts and strategies are used to enlist their participation. To explore one possible strategy for including deaf respondents as active participants in health surveys, the NCHS Questionnaire Design Research Laboratory (QDRL) conducted interviews with deaf subjects about the communicative, social, and practical aspects of administering survey questions via teletypewriter (TTY)² machines.

We had three purposes in mind for this test:

- To evaluate the feasibility of using the TTY to administer a health survey.
- To evaluate whether or not the mechanical limitations of the TTY (narrow screen size, slow speed of transmission) affect the survey process.
- To evaluate whether questions designed for oral administration to a hearing sample would be understandable as written English questions for deaf subjects whose primary language is American Sign Language (ASL). ASL has a different syntax than English.

METHODOLOGY

The Questionnaire

For this study, we used disability and health-related quality-of-life questions (CDC, 1998) developed for the Behavioral Risk Factor Surveillance System (BRFSS) to track how many persons view themselves as having a long-term activity limitation (i.e. disability) and how that affects their quality of life. The BRFSS is a state-based, random-digit-dialed telephone survey of community-dwelling U.S. adults 18 years of age and over. The questions ask about:

- number of days during the preceding 30 days when physical health was not good; mental health was not good; and usual activities were limited.
- any activity and/or work limitation resulting

from an impairment or health problem and its cause.

- whether human or mechanical assistance is needed for mobility or to perform routine daily activities.
- number of days during the preceding 30 days when subjects were affected by pain, depression, anxiety, or sleeplessness.
- number of days during the preceding 30 days when subjects felt very healthy and full of energy.

About Cognitive Testing of Questionnaires

Typically, the process of pretesting questionnaires in the QDRL is based on a cognitive model of survey response that describes four steps taken in responding to a survey question:

1. Comprehension of the meaning of the question
2. Retrieval from memory of relevant data
3. Judgment about how well the recalled material fits the question
4. Response

For this study we used retrospective protocols or thinkalouds, with paraphrasing and probing (Sudman et al., 1996). After the interview was administered over the TTY, the interviewer joined the subjects and asked how they went about deciding on their answers.

Ideally, a survey designer has carefully determined what information needs to be collected and has arranged an efficient and concise set of questions that will elicit valid answers. Very often, the questionnaire designers are so imbued with the concepts, vocabulary and perhaps jargon of the research, that they are unable to realize how specialized their view has become. By pretesting questionnaires on novices from a variety of backgrounds, potential sources of invalid data are identified and suggestions for improvement can be made.

Recruiting Subjects for Cognitive Testing

Deaf and hearing impaired subjects were recruited through an advertisement on the Internet in a deaf newsletter, with flyers distributed at a cafeteria known to be frequented by deaf adults, and through a flyer

distributed to a deaf senior group. A \$30 incentive was offered.

Two rounds of interviews were conducted, the first with ten subjects in the summer of 1997 and the second with nine subjects in the winter of 1998.

The subjects came to the laboratory, met the interviewers, and were asked to sit in a private room. They received and answered survey questions using a TTY for both rounds. The interviewer used a TTY in the first round and the Nexcom Modem³ attached to a desk top computer in the second. The Nexcom standardized question presentation and increased delivery speed. Interviews were videotaped.

Following the TTY survey, deaf subjects were debriefed by a cognitive lab interviewer and a deaf researcher, assisted by an ASL interpreter. The purpose of the debriefing was to discuss the subjects' reactions to the survey and to identify problems that made certain questions hard for deaf subjects to understand or answer.

It should be noted that the subjects recruited for this study had been deaf since birth or early in life and may differ in some ways from those who lose their hearing later in life. Because such differences may affect performance in survey situations, the findings of this study may be generalizable only to the former group.

FINDINGS

Findings Regarding Equipment:

- For long questions, only portions of a question could be viewed at any one time on the TTY screen.
- TTY equipment transmitted the questions and response alternatives as a continuous stream of text, which was difficult to read, rather than formatting the question as it would appear on a printed questionnaire.
- At the end of 24 characters, words were split onto new lines, which made some questions confusing.
- Occasionally the equipment malfunctioned (connections were broken, questions became garbled). The use of the Nexcom in Round II considerably improved delivery of the questions.

Findings Regarding the Methodology of Cognitive Testing Questionnaires for Deaf Respondents:

Recruiting this hard-to-find population took more time and effort than is typical for QDRL studies. Many deaf people were reluctant to participate in the study because they were concerned about the adequacy of their

English skills. Also, lack of survey experience made deaf persons unsure of what they were being asked to do. Having a deaf researcher to contact and reassure potential subjects was important to the success of the project. During the cognitive debriefing, many subjects said that if they were contacted at their homes they would be reluctant to answer a survey from strangers over the telephone. They would need to be convinced that it was being done by a credible organization for worthy reasons, and that it was important to the deaf community.

Sign Language interpreters had to be located and coordinated with respondents' availability. Moreover, the skill of the interpreter was another element in the success of an interview. We found that professional sign language interpreters varied in skill level and on occasion could not meet the language needs of the deaf subject. Fortunately our lab manager has knowledge of sign language and, together with the deaf researcher, was able to manage the interviews so that most went well. But even when interpreting was going well, typical cognitive lab techniques for studying questionnaire design, such as thinkalouds and probes about word meaning, were very hard to use because all communication had to be relayed through the interpreter.

Findings Regarding Comprehension and Interpretation of the Questions

- In general, our deaf subjects did not report deafness as causing a limitation of activity. In response to, "*Are you limited in any way in any activity because of an impairment or health problem?*", only a few mentioned deafness. In the debriefing after the TTY interviews, subjects explained that they are not impaired, not limited, not disabled. They are deaf, *period*.
- Again, when asked, "*Are you limited in the kind or amount of work you can do because of an impairment or health problem?*" Only a few subjects mentioned deafness. Others either said they were not limited at all or cited some other health problem as a limitation, such as a heart condition.
- Many of the BRFSS questions asked for a number of days during the past 30 days when there was a symptom or a limitation of activity. This kind of question was hard for subjects to answer in terms of a number of days.
- In the cognitive debriefing, narrative descriptions of subjects' health seemed to contradict responses to questions about the

number of days that health was not good. Fewer days were reported than the narrative would imply.

DISCUSSION

The results showed that it is technologically feasible to deliver questions and receive answers by TTY, at least with the deaf subjects we recruited. This mode does, however, pose some limitations. Because only a small amount of text can be read at any time, longer questions may not work as well through a TTY. Consequences of this might include respondent fatigue, which could lead to a decrease in response quality or breaking off the interview.

Interviewing deaf subjects also poses some challenges that are unrelated to technology. In our interviews, we observed that they often had trouble answering within the format specified by the question. Even though some questions clearly called for a numeric response, subjects tended to provide narrative, explanatory answers. Of course, this problem is not necessarily unique to deaf subjects (see below), but we suspect that it may be more pronounced due to their inexperience as survey respondents. Although some deaf subjects reported occasional participation in self-administered surveys (often aimed specifically at the deaf population), few, if any, had participated in general population surveys conducted through face-to-face or telephone modes (TTY). Surveys are unusual communication events, following some conversation norms but not others (Schaeffer, 1991). To someone without experience, it might not be obvious that the interviewer actually seeks a simple quantitative response and nothing more. Fortunately, we gathered some evidence that it is possible to “train” respondents about desired format, even through a TTY. In our later interviews, we suggested explicitly that subjects answer only with a number or letter indicating a specific response category. That preparation, plus a few reminders such as, “So how many days would that be?”, usually elicited an answer in the desired format.

Language barriers pose another challenge for interviewing deaf respondents. Many people assume that American Sign Language (ASL) is the same as English, simply rendered visually. This is not the case— it is a unique language with its own syntax. It must actually be *translated* into English, just as Spanish or French would be. Furthermore, ASL may be the *first language* for deaf respondents. Communication problems posed by the use of a different language may be seriously underestimated. Our subjects did not understand some English words well, such as “impairment” (which appeared in several questions), because the words translate poorly into ASL.

At other times, English syntax seemed clumsy to our subjects (“[It’s] such a *hearing* survey!”) A number of them expressed the preference that surveys should be conducted in ASL rather than written English. This may not always be feasible— but since there is a continuum of English competence in the deaf community ranging from marginal to mastery, further research should be conducted on the comparability of written TTY instruments to ASL translations.

Cultural differences between hearing and deaf may also play a significant role in the interpretation of key concepts. For example, not only is the term “impairment” difficult to translate, but deaf subjects also seemed to define it in a broadly different manner than expected. One question asked whether respondents consider themselves to be “limited in any way because of any impairment or health problem.” Most deaf subjects answered this question negatively, despite the fact that they cannot hear— which the survey authors surely considered to be an “impairment.” At first, we speculated that subjects answered negatively to avoid overstating the obvious. We already knew they were deaf, in effect, their answers could mean that they had no limitations *other than deafness*. Yet this explanation did not hold, since subjects later mentioned explicitly that they did not consider deafness to be a “limitation” at all.

Subjects’ responses make sense if we accept a different conceptualization of impairment. From a “hearing person’s” perspective, deafness clearly puts some limits on people. But many subjects said they were not limited because they *could* engage in broad activities they wanted to (e.g., work) even if they could not perform every imaginable job. They knew that being a telephone operator, for example, was not viable, but this was outside their expectations of what they would do. If they could not *work* more generally, then that would be a limitation. We obtained an additional perspective on “limitation” when one subject mentioned that she was unable to hear subway announcements. While certainly an inconvenience, she did not consider this to be a limitation. Her explanation was that the *system* is limited in that it does not make it possible for her to see announcements-- but the “limitation” does not lie with her. Such observations were fairly common in our interviews. Although we cannot be certain, we saw some indications that this alternative conceptualization may have been fairly strong throughout the deaf community, reflecting common cultural understanding rather than unusual individual interpretations. In any case, it is clear that relying on conventional understandings of the term “impairment” could lead to erroneous conclusions if the questions were administered to deaf respondents.

Of course, some problems reside in the questions

themselves. We believe that the questions do work under many circumstances. For example, questions about the number of days out of 30 are easy if the respondent did something “every day” or “never.” They are also reasonable for reporting discrete conditions (e.g., an illness that lasted 2 days). Other conditions are not discrete but occur in a regular pattern, which allows a respondent to estimate. For example, one deaf subject reported experiencing pain for 8 days of the past 30—she computed this by remembering pain in her hands from using sign language for hours after teaching classes twice a week over four weeks, rather than remembering each occasion.

However, many health conditions are neither discrete nor regular, nor do they translate easily into “days.” Many conditions may last for only parts of days (e.g., feelings of sadness that last several hours at a time); respondents must decide whether such experiences count as an entire “day” of feeling sad. Subjects also indicated that some of the health status conditions we asked about were not particularly salient to them—not enough to give more than a very broad guess (one subject remarked that she didn’t “keep records” on these matters). Although deaf subjects had difficulties with the questions for these reasons, the problems are not unique to the deaf, and have been observed among hearing subjects as well (see Beatty, Schechter, and Whitaker, 1996).

CONCLUSIONS

Our study has shown that the TTY can be used to survey the deaf, at least the large segment of the deaf population that is like our subjects. The results may be less applicable to other segments. Based on our findings, however, certain issues need to be addressed:

- Special recruitment efforts would be needed to survey deaf respondents. The deaf are suspicious about answering personal questions because callers cannot be positively identified on the TTY. An advance letter from a reliable source would help convince them.
- A TTY survey should include a straightforward question asking whether the respondent is deaf. Deafness is not necessarily viewed as an impairment, limitation, or health problem.
- Since many deaf people are inexperienced with surveys, the introduction to the survey should provide examples of how a one-letter or one-number response from response alternatives can minimize the effort of response.

- The narrow 20 character visual display on the TTY imposed a memory burden for long questions. Questions would be easier to answer if they were shortened and simplified.
- During the TTY survey, numerous requests were made for definitions of health-related vocabulary. Hence, interviewers should have a manual of standard definitions.

As near as we were able to ascertain, if deaf subjects fall into a survey sample, large scale survey organizations seem to handle the situation on an *ad hoc* basis. Anecdotal stories suggest that interviewing deaf subjects has proved to be expensive and frustrating, often resulting in another family members being used as a proxy. It is our hope that procedures can be improved so that deaf respondents can participate directly in surveys. Several steps would make this possible: first, researchers could educate the deaf community about the value of survey research and the integrity of major research institutions, and the importance of individual deaf respondents’ participation. Second, survey institutions could implement procedures to identify and include deaf respondents when they fall into samples, which may include programming questionnaires onto a TTY or training interviewers in ASL. Third, questionnaires could be modified to correspond to unique circumstances of deaf respondents, and perhaps to reflect an understanding of deaf culture as well.

Clearly, these initiatives would require effort and expense, and some researchers will undoubtedly be skeptical that the benefits would justify the costs. Unfortunately, we have little information on which such decisions can be based. Perhaps the most urgent research initiatives should be directed toward understanding how much data is lost due to current barriers against the inclusion of deaf subjects, as well as the current quality of data involving deaf respondents. If practical procedures to include deaf respondents are to be incorporated, it will be critical to gather more data about the costs involved and the benefits secured by such advancements.

Future Objectives

- Test a more representative sample of deaf people who have various educational levels. The average reading level for a deaf high school graduate is between third and fourth grade (Farwell 1976).
- Study how cultural differences in the deaf community affect responses to certain topics and survey questions.

- Develop training procedures for phone interviewers who reach TTYs. Without training, it is likely that the audio tones made by TTYs are erroneously identified as FAX machines and the call is disconnected.
- Compare other modes of survey administration (face-to-face, mail, self-administered questionnaire, Internet, Email, Video-remote communication) to the TTY method to determine the drawbacks and benefits of each.
- Increase outreach to the deaf community regarding the importance of their inclusion in health surveys.

personal communications software for computer-based TTY calls

- Requires at least 386 IBM compatible computer
- Utilizes computer monitor
- Outgoing messages are in lower case
- Incoming messages are in upper case
- Standard memory allows for the pre-programming of 24 survey questions
- Able to save conversation in any file format

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Footnotes:

¹According to the National Health Interview Survey of Disability, 1994, 10 million persons are hearing impaired to the extent that they have difficulty hearing a normal conversation even while using a hearing aid.

² A TTY is a machine with a keyboard, a narrow screen, and a phone cradle that converts electronic impulses into typed letters that move across the screen. Characteristics of the TTY with Built-In Printer:

- 45.5 Baud rate (Baudot code)
- 20 character visual display
- 24 character built-in printer
- visual messages are displayed in upper case letters
- cannot preprogram survey questions
- cannot electronically save conversation

³Characteristics of the Nexcom Modem

- TTY compatible high speed modem with

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