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Abstract

Background: Health care providers commonly discuss depressive symptoms with clients, enabling earlier intervention. Such discussions rarely occur between providers and Deaf clients. Most culturally Deaf adults experience early-onset hearing loss, self-identify as part of a unique culture, and communicate in the visual language of American Sign Language (ASL). Communication barriers abound, and depression screening instruments may be unreliable. **Purpose:** To train and use ASL interpreters for a qualitative study describing depressive symptoms among Deaf adults. **Method:** Training included research versus community interpreting. During data collection, interpreters translated to and from voiced English and ASL. **Results:** Training eliminated potential problems during data collection. Unexpected issues included participants asking for “my interpreter” and worrying about confidentiality or friendship in a small community. **Conclusions:** Lessons learned included the value of careful training of interpreters prior to initiating data collection, including resolution of possible role conflicts and ensuring conceptual equivalence in real-time interpreting.

Keywords

mental health, transcultural health, culturally Deaf, translators, interpreters

The purpose of this article is to describe the adaptations necessary when using American Sign Language (ASL) interpreters to facilitate research with culturally Deaf adult participants. Consideration for culturally sensitive research must include functional equivalence, defined as the ability of a concept to perform or elicit similar responses in two or more cultures (P. Jones, Lee, Phillips, Zhang, & Jaceldo, 2001). Engaging in dialogue with culturally Deaf adult participants necessitates interacting in the participants’ preferred language of choice. Phrases and terms used in the dialogue must be meaningful to the population (Pollard, 2002).

The role of an ASL interpreter consists of more than merely translating from spoken English to signed ASL. The ASL interpreter must understand the unique syntax and structure of ASL (Lieu, Sadler, Fullerton, & Stohlmann, 2008). He or she must be able to “read” the Deaf adult’s facial expressions and body language and incorporate these tacit communications into the overall context of the dialogue. The ASL interpreter must possess an understanding of the Deaf culture. For these reasons, the translator is more aptly called an ASL interpreter (Hoza, 2008).

As part of a preliminary study that informed my dissertation (Sheppard, 2008), I developed questions to be used during an interview with culturally Deaf adults. The process included translating and back-translating interview questions between spoken English and signed ASL. This ultimately led

to the development and refinement of interview questions that were used in my dissertation research and were important in identifying several methodological pitfalls. The dissertation research included 27 interviews with culturally Deaf adults and described the ASL signs and phrases that expressed the Deaf adult’s perspective of depressive symptoms (Sheppard, 2008).

ASL interpreters formed an integral part of both the preliminary and dissertation study. Although I am conversant in ASL, I employed three certified interpreters to ensure that concepts were accurately described and discussed. This article describes the process of ASL interpreter recruitment, training, translation, and back-translation as well as the role of the interpreters during consent procedures and data collection. Unexpected challenges arose throughout the study process and these too will be described. Finally, I will discuss what worked, what did not work and why, and what I learned in the process.

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Background

Depression is the greatest cause of nonfatal burden socially and economically, worldwide (Schotte, Van Den Bossche, De Doncker, Claes, & Cosyns, 2006) and is the most common mental health disorder. Symptoms of depression may cause physical, emotional, or cognitive manifestations of mood alteration that interfere with everyday life activities over time. Failing to identify or discuss depressive symptoms increases the risk of missing signs of clinical depression and even suicide (Murray et al., 2006). Health care providers commonly discuss depressive symptoms with their clients (Fraguas et al., 2006), which can lead to earlier identification of those at risk for depression. Many health care providers even manage depression or depressive symptoms in the primary care setting, thereby reducing morbidity and mortality (Belnap et al., 2006). However, as noted by Montoya et al. (2004), health care providers often fail to discuss depressive symptoms with their culturally Deaf clients in part because they are not adequately trained to assess or discuss depressive symptoms among culturally Deaf adults.

Culturally Deaf adults are those individuals who lost their hearing at an early age, often prelingually (before the onset of speech development), who prefer to communicate in the visual language of ASL, and who self-identify as members of the Deaf community (connoted by upper case "D"). Members of the Deaf culture have a common knowledge and a collective memory that is used to communicate; this way of knowing is learned and shared over time and guides thinking, behavior, and decisions in a common way (Stebnicki & Coeling, 1999). The uniqueness of the Deaf culture must be considered in any physical or mental aspect of the health care assessment.

There is no evidence in the literature to suggest that culturally Deaf adults do not experience depressive symptoms, but methods of assessing depressive symptoms among this population are unreliable and inadequate for the health care setting. Some studies have described Deaf adults' experiences receiving health care; descriptions from Deaf patients include feeling frustrated and discouraged, believing that care has been substandard, and never having discussed any depressive symptoms (Barnett, 2002; Pollard & Adams, 2004). Differences in communication, culture, and linguistics between health care providers and culturally Deaf adults often lead to misinterpretation, misdiagnosis, and stereotyping (Steinberg, Wiggins, Barmada, & Sullivan, 2002). Depression screening tools may be unreliable for Deaf adults because they have not been adequately translated and validated (Young, Tattersall, Uus, Bamford, & McCracken, 2004). Leigh and Pollard (2003) found that depressive symptoms among culturally Deaf adults are frequently missed, and it is estimated that only 2% of culturally Deaf adults ever receive the mental health care they need. Improved assessment of depressive symptoms and identification of those at

risk for depression are critical priorities in health care and have been designated by the National Institute of Mental Health (Jackson et al., 2004) as high priority. Improvements in care and communication must begin with open dialogue and mutual understanding between providers and their culturally Deaf adult clients.

Cultural Context

Diversity is not limited to ethnicity. Culturally Deaf adults are members of a distinct culture, with a unique language, ASL. Members of the culture are bound together by the experience of deafness, which offers a distinctly different perspective of the world (Dolnick, 1993). Sparrow (2005) proposes that the concept of a Deaf culture falls best within the ethnic or national culture paradigm. The cultural model offers a clear distinction between the hard-of-hearing or deaf individuals who communicate with spoken English and those who self-identify as culturally Deaf and communicate visually.

It is quite common for both providers and clients to face language barriers and translation challenges in health care encounters. For example, four health care institutions within this study's geographical recruitment area have made considerable efforts to address the needs of clients such as Spanish, Hmong, Laotian, Russian, Cambodian, and Mandarin speakers. However, translating from English to ASL is different from translating from one spoken language to another (E. Jones, Mallinson, Phillips, & Kang, 2006) because it has the added complexity of going from the visual language of ASL to spoken English. Furthermore, terms such as *depression* or *self-esteem* are not easily translated from English to ASL (Vernon & Miller, 2001).

It is through ASL that expression of values, beliefs, traditions, history, humor, and arts are shared. ASL is considered to be the most natural language for the Deaf, as it allows members to communicate without conscious effort (de Halleux & Poncelet, 2001). ASL has no written language tradition of its own. Facial expressions are extremely important in ASL communications and are often used to augment the meaning of an ASL sign or phrase, to emphasize a thought or feeling, or to convey varying intensity. When concepts such as self-esteem become confusing to the Deaf client or difficult to translate, interpreters may unintentionally lead the conversation in a different direction in their attempt to assist and clarify (Vernon & Miller, 2001). In addition, there may be varied levels of understanding among culturally Deaf adults that are especially important when seeking volunteer participation and obtaining written consent for research purposes.

Expectations and Outcomes

Although my doctoral coursework and research experience had prepared me for numerous methodological issues, working

with interpreters added an additional unpredictable dimension to the research process. As a family nurse practitioner, I have provided health care to many members of the Deaf population who lived within the research recruitment area; however, engaging as a researcher within this population necessitated a complete role transition. Challenges included locating and retaining qualified interpreters, training interpreters to work in research settings, and translating interview questions and participant responses.

Seeking Qualified Interpreters

To maximize understanding between the investigator and the participants, I wanted to hire highly skilled interpreters who could contribute in significant ways to my research. Given the population of Deaf adults living within the recruitment area, I expected that certified and experienced ASL interpreters would be easy to locate and hire. The criteria that I had set for ASL interpreters included an advanced level of certification and a minimum of 5 years of recent experience as an interpreter. I wanted to hire ASL interpreters who had experience interpreting in research and mental health encounters, as well as experience interpreting in the health care environment. I additionally considered interpreter salary expectations, availability, and scheduling conflicts, and finally, I sought those with an interest in the topic of depression among Deaf adults.

Although I expected that recruitment of Deaf participants would be a lengthy process, I did not expect that recruiting and hiring certified ASL interpreters would be difficult. In fact, procuring certified interpreters took far longer than recruitment of the study participants. My first surprise in recruiting interpreters was to learn that there was no central ASL registry within the state where the study was to be conducted. I learned that the closest registry for certified ASL interpreters is located several states away. So, I then inquired at the three local hospitals within the recruitment area, and at each location, I was referred to the central registry out of state. Flyers soliciting interpreters for hire were then posted at health care facilities, churches, state organizations, and academic institutions. I ultimately located the names of two interpreters through university disability centers and made initial contact with these two interpreters.

It became clear to me as I began to interact with potential interpreters that each had assumed a role as gatekeeper to the Deaf culture as well as interpreter. When I contacted the two interpreters by telephone to describe the study purpose, both stated that the study sounded interesting and even important, but they wanted to know why I was interested in studying Deaf adults. Both interpreters indicated in the telephone conversations that they wanted to protect the members of the Deaf community. Appreciating their concern, I asked to meet each of them in person. I met with each interpreter and using ASL, introduced myself and described the purpose of

my study. Immediately, the entire demeanor of each interpreter changed. As I demonstrated my own skill and understanding of ASL, the interpreters expressed their interest and enthusiasm for the study and offered to participate.

Within 1 week of meeting with the two initial interpreters, I was contacted by seven other certified interpreters who had heard about the study and wanted to participate. I realized that establishing credibility was crucial to the success of the study—not only credibility with the Deaf participants themselves but also with those who serve as gatekeepers, including interpreters. From start to finish, the process of locating and hiring three interpreters for the pilot study and my dissertation took 6 months.

Negotiating

I anticipated that hiring an interpreter would be somewhat costly and that there would be little variation in the requested rate of remuneration. In fact, rates and fee schedules varied widely, ranging from \$25.00 to \$50.00 per hour. Some interpreters asked to be paid for their travel time to the interview location, some requested a minimum of 1 hour's work, and some billed in hourly increments only. The interpreters and I identified the number of training hours and negotiated appropriate salaries through mutual dialogue and discussion. For example, all interpreters were required to complete an online Human Subject Protection training program; each interpreter was paid for 5 hours to complete this course. I agreed to pay for any additional training hours, and the interpreters waived their requested fees for travel. To my surprise, the interpreters each reduced their hourly rate, volunteering that they believed in the need for the study.

Training and Interviews

Three certified ASL interpreters were hired for this study. Each interpreter completed the Human Subject Protection online program and received certification. Although I had anticipated that much of the content would be challenging, I expected that the interpreters would be able to navigate the computer program fairly easily. However, all three of the interpreters contacted me saying that they were having difficulty just establishing their sign-in to start the program. I quickly realized that the computer program was not user-friendly to the uninitiated. To enable the interpreters to absorb the content and successfully complete the certification, I developed a PowerPoint presentation that took the interpreters through every step; this began with establishing a sign-in and password and ended with submitting the tests for certification (correct answers to test items were not provided).

After the interpreters successfully completed the Human Subject Protection certification, I met with each to review the role of the interpreter in research. Although each interpreter

had extensive experience in community and health care settings, none had ever participated in a research study. Training therefore addressed the differences between these settings. For example, when interpreting in a health care setting, the interpreter may help clarify misunderstandings. In the research setting, it was explained that the interpreter should not help fill in missing information or attempt to offer clarifications without discussing any misunderstandings with the researcher.

The training included sample interviews between myself and a Deaf volunteer. After developing interview questions, I reviewed all questions with an interpreter and a Deaf volunteer. I asked questions in English, the interpreter signed from spoken English to ASL, the volunteer participant responded in signed ASL, and the interpreter voiced from signed ASL to spoken English. After completing a sample interview, all three of us reviewed the interview questions to identify potential areas of confusion or lack of cultural validity.

The actual participant interviews were videotaped to capture the facial expression and body language of the participant; this became important during review and analysis, as facial expressions are used by Deaf adults to emphasize a point, to qualify and quantify statements, and to enhance the ASL signs. The videotapes also recorded my voice as well as the voice of the interpreter. Reviewing the videotapes helped contextualize interpretations in the event the interpreter or I had difficulty in following the dialogue.

Translating the Consent Form

As ASL has no written equivalent, an important part of the study was to translate the University of Arizona Human Subject Protection–approved written English consent form into ASL. One certified interpreter translated the written English consent into ASL; this was recorded onto a DVD. In this way, each Deaf participant could watch the DVD on a laptop prior to signing the written consent. The first participant interviewed demonstrated complete understanding of both the written English consent and the ASL-signed DVD consent. Unexpectedly, the second participant did not fully understand some components of the ASL-signed consent. A second DVD was thus made, using simpler ASL signs, and the participant was re-consented. After realizing that at least 1 participant had some confusion with the DVD, the interpreter was present during the consent process to assist with questions or concerns. Participants were given a copy of both the written English consent form and the ASL/DVD-generated consent form.

Scheduling Interviews With Interpreters and Participants

Scheduling needs required ongoing negotiation. Each interpreter was employed elsewhere in a full-time job, so interviews

with Deaf participants were scheduled around the interpreter's work schedule. The interpreters and I anticipated that approximately 20 to 30 interviews would take place. Ultimately 27 interviews were conducted, each lasting approximately 45 to 60 minutes. Unfortunately, numerous unexpected events occurred that created scheduling difficulties. Over the course of the data collection process, it readily became apparent that certified ASL interpreters were in great demand. At least half of the 27 interviews had to be unexpectedly rescheduled because the interpreter was called away for an "emergency." Emergencies included an interpreter being asked at the last minute to interpret for a presidential candidate, a Deaf patient in the emergency department, or a Deaf person being arrested and arraigned. Although the nature of these emergencies was understood, the last-minute cancellations and rescheduling were time consuming and frustrating for all involved. We learned to use cell phone text messaging to confirm time and locations of all interviews, and it readily became apparent that text messaging is of great benefit for the Deaf community.

Uniqueness of Participants

The Deaf community within this research study location is relatively small and everyone seemed to know each other. This created some problems as a given participant might not want a certain interpreter present, so I identified the name of the interpreter prior to each interview. As expected, several participants declined to have a specific interpreter present because either they were personal friends or feared a breach of confidentiality. Several participants asked to provide their "own" interpreter. After conferring with my dissertation committee and Human Subject Protection, I accommodated this request by having both the study interpreter and the participant's own interpreter present.

I anticipated that I would not be able to follow the entire content of the ASL dialogue and presumed that my understanding would be far inferior to that of the interpreter. For this reason and to enhance the quality of the data analysis, all interviews were videotaped. A second interpreter reviewed the taped interviews to confirm the accuracy of ASL interpretations. Unexpectedly, the signing of several of the Deaf participants was difficult for both the interpreter and me to understand. In these cases, we halted the interview, conferred about the difficulties, and asked the participant for clarification. Whenever there was a doubt about the interpretation, two interpreters and the researcher reviewed and clarified the videotapes.

Interpreter Embellishments

I expected that the interpreter would consider facial features, body language, and ASL signs as important components of the interpretation. There were occasions in which the participant

used an ASL sign to indicate an emotion such as “afraid,” but the interpreter voiced the word “terrified.” Deaf adults use facial expressions to emphasize meaning and severity (Barnett, 2002), and when words such as “afraid” are not accompanied by the customary facial expressions, it can create confusion in interpretation. When these situations arose, the interpreter and I discussed the terminology and ASL sign, and asked the participant for clarification. Two interpreters and I reviewed all video recordings when there were further concerns about translations.

During numerous interviews, I became aware that the interpreter was voicing words that were not coming from the participant, words such as “you know,” “like,” and “um.” Transcribing from the spoken/interpreted tape recordings to word format became an unexpected and at times very difficult task, as I had to separate out what the participant signed from the words and phrases added by the interpreter. In retrospect, this should have been better addressed during the training process and practice sessions.

Recommendations and Conclusions

Conducting interviews in the participant’s most natural language enables the researcher to capture the essence of the participant’s experience (Pollard, 2002). When the participants are Deaf adults, this may require working with certified ASL interpreters. Although the process of recruiting and training interpreters can be time consuming, skilled ASL interpreters also contribute to the quality of the study (Pollard, 2002).

Gatekeepers are found within health care delivery and health care research; these individuals hold key roles within a community or population and can facilitate or hinder the researcher’s access to members of the population (Lee, 2005). ASL interpreters may feel a deep commitment to the population they work with and may even assume the role of gatekeeper (Angelelli, 2006) as they did in this study. Interpreters may also view themselves as facilitating the creation of a safe environment (Rosenberg, Seller, & Leanza, 2008). Therefore, I would urge the researcher to establish credibility with potential interpreters to elicit their support rather than face unanticipated barriers accessing the population of interest. For example, after sharing the study purpose and format with the prospective interpreters, I observed enhanced buy-in and commitment to the project. It was my experience that when the interpreters viewed me as having genuine interest in the population rather than seeing the population merely as a source of data, they became supporters of the research study and even provided introductions within the Deaf community.

The process of interpreter recruitment, training, and scheduling can present an unexpected time challenge. In fact, one research team described their need to use the services of noncertified ASL interpreters for data collection

when certified interpreters were not available in the time frame allowed (Murray, Klinger, & McKinnon, 2007). The risk in using the services of a noncertified ASL interpreter includes potential loss of meaning and understanding (Meador & Zazove, 2005). Training will usually include providing interpreters with the means to complete Human Subject Protection training. Training sessions should also address the difference between translating in the community and the research setting; practice sessions should include sufficient time to conduct translation–back-translation exercises (E. Jones et al., 2006). In retrospect, I realize that additional training and repeated practice might have helped reduce the interpreter’s use of noncontributory mutterings, as ultimately if these were too disruptive I would have had to seek a different interpreter. For maximum flexibility with scheduling, I also found it helpful to have several trained interpreters ready to participate in the study. In terms of scheduling and confirming the time of the interviews, I learned from the interpreters that many Deaf adults rely on text messaging and the Internet; I found this helpful to ensure that everyone had the same understanding of meeting time and location.

Working with experienced ASL interpreters furthered my own understanding of the Deaf culture and the uniqueness of each individual within the culture. The interpreters were eager to share their own positive experiences and difficulties interpreting for clients/patients in health care settings. I viewed the interpreters as valuable culture brokers who provided me with alternative phrases that might have more meaning and understanding for Deaf adults.

Although working with interpreters often adds expense, time, and challenges to a research study, it can also afford benefits. Interpreters can serve as helpful bridges between the researcher and the cultural community. It is important to treat the interpreters as professionals and with respect for their ability and knowledge. Starting and ending the sessions at the agreed on time demonstrates respect for both the participants and the interpreters. Above all, flexibility and a sense of humor are invaluable.

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