

SPECIAL ARTICLE

AMERICAN SIGN LANGUAGE AND END-OF-LIFE CARE: RESEARCH IN THE DEAF COMMUNITY

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Overview

We describe how a Community-Based Participatory Research (CBPR) process was used to develop a means of discussing end-of-life care needs of Deaf seniors. This process identified a variety of communication issues to be addressed in working with this special population. We overview the unique linguistic and cultural characteristics of this community and their implications for working with Deaf individuals to provide information for making informed decisions about end-of-life care, including completion of health care directives. Our research and our work with members of the Deaf community strongly show that communication and presentation of information should be in American Sign Language, the language of Deaf citizens.

Carl, a Deaf person, had a brain tumor that affected his ability to use his hands, arms and body to sign clearly (1).¹ Despite the tumor, Carl retained some ability to produce the facial expressions of American Sign Language (ASL), enabling him to communicate in a limited way with family members. Carl's signs were most readily understood by those for whom ASL was their first language, as opposed to a hearing person who had learned to sign. For Carl, a Deaf hospice volunteer made the difference—giving Carl a little enjoyment and lessening his isolation as the only Deaf person in the nursing home.

One day, Carl's Deaf hospice volunteer and two hearing visitors brought him into the nursing home garden to enjoy the fresh air. Carl, like most elderly Deaf people became more animated when he saw someone who could sign; he knew immediately which visitors were Deaf and

noticeably relaxed as he shifted from the stress of communicating with hearing people into the easy expression of thoughts with other members of a shared language community.

In the course of the conversation, Carl began making small gestures of barely legible signs. The Deaf volunteer announced, "Carl needs to go to the bathroom!" Carl's hearing visitors (one of whom was an ASL interpreter of 20 years) had not recognized what Carl had signed. "Look at his hand," the Deaf volunteer said, directing their attention to nearly imperceptible movements by which Carl formed "T," the ASL sign for "toilet." This experience brought home the stakes involved in caring for members of a linguistic and cultural minority at the end of their lives. If the native ASL signer had not understood what Carl was 'saying,' Carl's caregivers might have concluded that Carl was incontinent. Diapers would have added to his loss of dignity and control.

The End-of-Life Care Education Project of the Minnesota Deaf Community (hereafter: Project) is a three-year collaboration of Deaf and hearing people. It has created new programs to recruit and train Deaf hospice volunteers, to provide workshops on health care directives co-facilitated by Deaf people and hospice practitioners, and to develop and disseminate educational materials about end-of-life care topics. From experiences with patients like Carl, the Project team recognized the need for more reliable information about Deaf people during end-of-life care. What did older Deaf people know and believe about this topic? What did they believe they needed to know? How could educational materials about end-of-life be better designed to reach elderly Deaf people?

This essay examines some of the unique linguistic and cultural differences of the Deaf community and their implications for the end-of-life care for this population. We also describe the experience of using Community-Based Participatory Research (CBPR) to engage Deaf people in identifying specific ways to improve end-of-life care (2)(3). We will show how this experience illustrates the necessity of having Deaf people involved in all stages of research, data interpretation, and as caregivers in the emotional and value-laden area of end-of-life care.

ASL: A language for its culture

American Sign Language (ASL) is the language used by members of the Deaf community. Up to two million Americans use ASL for everyday communication(4). The language and culture of the Deaf community differs from the experience and culture of all spoken linguistic minority groups. The extent to which it differs affects all aspects of end-of-life care and assessment of care needs. ASL is a visual language with its own grammar and syntax. It has no written form and can only be represented using a visual medium such as videotape. In using hands, facial expressions, body movements and space, it differs greatly in its transmission and use from any spoken and written language.

The difference in language modality affects access to information, particularly complex information related to health care. Like any language that borrows terms from another language, ASL may use an English term generally representing it by fingerspelling. Yet, ASL is not “English on the hands,” nor is it derivative of English vocabulary or grammar (5)(6). A new word for example, such as “hospice,” is fingerspelled until the concept is understood and used in conversation. In April 2002, a member of a Deaf Seniors Club introduced a sign for hospice—that sign now has a cultural life and meaning of its own. Though the adjective “American” is applied to ASL because Deaf people of North America use this sign language, ASL provides no immediate or general access to the English language or any other second language.

Hearing individuals may not immediately grasp the profound difference between acquiring a spoken language by hearing the language, and relying wholly on learning a language in its written form. ASL is acquired naturally; concrete experiences and abstract concepts are transmitted with the immediacy of a spoken language (7)(8)(9). Nevertheless, the task of composing a grammatically correct English sentence without the benefit of modeling by hearing conventional usage requires additional skills that must be painstakingly acquired (10)(11)(12)(13). Depending solely on English for communication with Deaf individuals invariably increases the probability of misunderstanding and stress.² Deaf elderly patients are not cognitively impaired, nor do they have limited life experience or suffer from an inability to communicate all the subtleties of emotion and ideas about their experience – in their own language. They will however, like most of us have difficulty communicating the full range of our experiences very well in a second language. In that the Deaf individual may need to attain English proficiency

to function in the hearing world, that hearing world has an ethical obligation to address barriers to communication in the important area of end-of-life care.

ASL: Challenges for research and clinical care

A brief summary of some of the key elements of the language will illustrate the depth of the issues Deaf people and health care professionals may encounter when communicating with one another.³ ASL, in summary, is a nonlinear language using space, facial expressions and hand and body movements, fully exploiting the capacities of vision, spatial relations, and visual-kinetic memory for storing and processing concurrent layers of information (14).

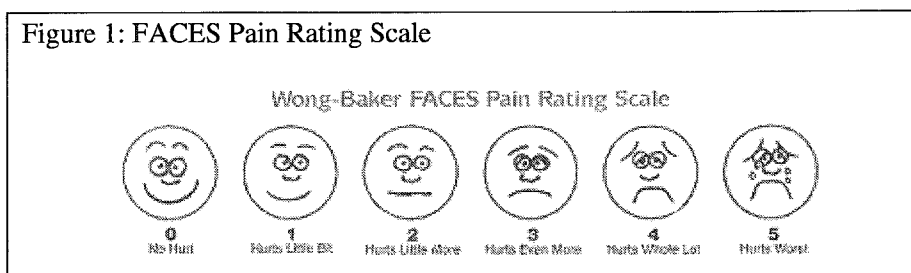
Facial expressions, “non-manuals,” convey meaning. They include adverbs and information about sentence structure and organization. For example, there is one sign for ‘pain;’ intensity and variations of “pain” are indicated by non-manuals. Therefore, a practitioner may know the hand shape and movement for the sign “pain,” but without the non-manual, assessing pain would be extremely difficult. Over 250 grammatically governed facial expressions are identified; these signifiers may be described, but since they involve subtle movements of face, tongue, eyes, eyebrows, lips, mouth, they cannot be represented as written symbols.

ASL also displays grammatical elements such as the actors and objects of actions spatially. By pointing to a space(s) in front of the signer’s body, the signer is able to use spatial arrangements to carry complex meanings that would require a lengthy text or explanation, if the same information were to be conveyed in a spoken or written language. The location of the sign relative to the body also carries information and can change the meaning of the sentence. Returning to our example using the sign for “pain,” the location of the pain is indicated by signing “pain” where the pain occurs. The hand shape and movement for the sign “pain,” performed in the location of the temple is the sign for “headache.”

The linguistic differences between English and ASL affect all communication, whether it is for purposes of conducting survey research or assessing pain. As noted above, sentence structure is determined by non-manuals and therefore signify and distinguish interrogative from declarative statements. For example, a “Yes/No” question must be marked by raised eyebrows; “Wh-questions” (what, where, when, why and how) must be indicated with eyebrows down. To ask the question, “do you have any pain?”

with eyebrows down is not only grammatically incorrect it makes communication confusing or incoherent to some Deaf people, particularly individuals who are seriously ill. Now consider the “Faces Pain Rating Scale” (Figure 1), a visual scale that often is used to help health care providers assess a patient’s level and type of pain (15)(16)(17)(18)(19).⁴ Raised and lowered eyebrows as used in the Faces Pain Rating scale have no linguistic association with pain in ASL.⁵ Rather, the facials illustrated in Figure 1 are the facial components of ASL signs for: happy, glad, surprise, depressed, sad, and cry (20).

Figure 1: FACES Pain Rating Scale



Numeric Pain Rating Scales (NRS), another popular pain assessment tool, rank order pain numerically along a horizontal continuum that is typically graded as an interval measure ranging from zero (no pain) to five (worst pain). As a nonlinear language, ASL does not identify the left as a point of initiation or the right as an end-point. As a result, the spatial importance of the scalar zero point and end points must be explained to Deaf persons if a horizontal scale is used – not for lack of ability to understand, but because the Deaf individual is being asked to translate prior to being able to respond to a question. Our research suggests that vertical scales may be more easily accessed by this population (21)(22).

Deaf culture: Who is “family”

Cultural differences and life experiences of Deaf seniors also can affect end-of-life care. Language and culture deeply shape each other (23). Deaf persons experience and share a unique enculturation that strongly influences the development of strong peer social networks. Given that nearly ninety-five percent of Deaf children have hearing parents, many Deaf people become separated by language and living arrangements from their birth

families. For these individuals this separation begins in residential schools where opportunities for intimacy and deep conversations with parents or siblings are greatly diminished. For the current elderly Deaf population, residential school was an environment in which students and teachers rarely shared a common language. In response to living in a kind of “information vacuum,” peer learning became a primary source of information. The reliability of information is more difficult to maintain in this smaller and more isolated network of peer learning (24, pp. 66-67). When stories are incomplete, people tend to speculate; as a result, they may misinterpret and misstate events in their effort to create a sense of coherence. In the case of healthcare information, the reliance on peer learning — in the absence of alternative sources of knowledge — may, indeed, place Deaf individuals at greater risk. Peer relationships have another relevant implication: for Deaf individuals, friendship bonds may be stronger than family bonds and the choice of a health care agent for medical decisions may be deferred to members of the friendship group that began in residential school.

Additionally, in the hearing environment, incidental information plays an important role in how people acquire and interpret new information. Conversations overheard at the bus stop, in the lunchroom, on radio or television, provide background knowledge upon which individuals and communities come to understand the “meaning” of terms such as “advanced directives” or “hospice.” Deaf people have no access to this incidental information.

Community-Based Participatory Research (CBPR)

To better understand end-of-life care for Deaf persons, we conducted survey research using a Community-Based Participatory Research (CBPR) process. Though the analysis of the data is not yet completed, the experience of developing this kind of research is noteworthy and should be helpful to clinicians, researchers, and ethics committees who are working with end-of-life care and Deaf persons.

Developing a Questionnaire: The Project team designed a draft survey covering seven areas: Obstacles in obtaining information, English reading, where people get information, communication with physicians, decision-making, perspectives on death and understanding about end-of-life care and hospice. Over a period of several weeks, the questionnaire was modified in consultation with approximately twenty members of the Deaf community selected for their experience in the community, leadership role in

a Deaf organization, or occupational expertise. These Deaf consultants helped identify questions that might be confusing, perceived as oppressive or as reflecting assumptions inappropriate to Deaf culture. Three individuals selected as interviewers were taught basic survey research methods and interviewer protocol and trained by role playing the respondents and interviewers. Following initial tests and discussions with this group, we refined the questions and redesigned the visual format of the questionnaire. Following a pilot test with elderly Deaf persons living in the Minneapolis/St. Paul metropolitan area, a lead interviewer was videotaped signing the questionnaire. In addition to face-to-face training sessions, all interviewers were given a copy of this videotape as a practice tape.

The first night of interviewer training demonstrated the weakness of our initial plan to rely completely on the practice tape as the model. The written survey questions continued to be open for individual interpretation, making it difficult to achieve consistency in signing the questions – a key to obtaining reliable data. In the ensuing critique of the survey instrument, the research attained a new level of community-based participation. Even as we reached consensus on the wording of the questions, differences remained on the specific signs that best represented the meaning of the question and on what inflection should be used in distinguishing the intervals on our linguistically adapted Likert scales.

Ultimately we arrived at a consensus by employing an ASL linguistic method that allowed us to change English into “GLOSS,” and reconstruct the survey in a uniquely “Deaf” final form. GLOSS means using English words that represent ASL signs in their most common meaning as a method of conveying the sign in a written English form. GLOSS is not a written form of ASL, nor is it the same as translating, but like translating, writing GLOSS is an advanced skill. The English words appear in upper case and in ASL word order. We were fortunate that Deaf individuals participating in the research were able to identify the importance of using this linguistic method and had expertise in this area. GLOSSING proved to be the methodological discovery that allowed us to remove the linguistic barrier that threatened the study’s reliability and validity. It provided a method for arriving at consensus among the Deaf interviewers about how a question needed to be signed to assure adherence to the intended purpose and meaning of the question.

- An English-to-GLOSS question may read: “If Deaf people get very sick and are dying, a skilled interpreter should be available to them and their families at all times. How important is this?”

- Its GLOSSED equivalent may read: IF DEAF PERSON SICK (facial meaning “very”), CLOSE-TO DEATH, [mmm mouth and eyebrows down] INTERPRETER MUST READY, GO-GO-GO FOR SELF [body shift] FAMILY, IMPORTANT HOW-MUCH?”

Likert scales posed additional challenges. Based on strong advice from a Deaf psychologist, we changed the horizontal scale to a vertical scale. As noted, adverbs are indicated by non-manuals; the difference between “very important” and “important” is shown by a change in facial expression, the basic sign for “important” remains the same. We discovered that these facial signs are universal and are reliably communicated by various interviewers and respondents. Furthermore, ASL does not use double negatives making phrases like “not important” nonsensical. GLOSS was also used in translating English words used in the Likert Scale. For example, “Not very important” became “IMPORTANT LITTLE” and “Somewhat important” became SO-SO. The final copy of the highly formatted instrument was 22 pages and was designed to take 30 minutes for asking 64 questions.

Conclusion

Members of the Deaf community belong to a distinct linguistic and cultural minority group. As such, their life experiences have an impact on all aspects of end-of-life care. The most identifiable characteristic of Deaf people is their language. American Sign Language is not a “choice” — it is the language of the Deaf community. Access to information in their language was clearly identified as barrier that affected an individual’s ability to understand ones illness and make decisions about end-of-life care — including choosing a health care agent. More opportunities are needed for researchers, members of the Deaf community and practitioners to work together to identify specific interventions to address the unique linguistic differences of this population. Our experience in designing our research points out many of the pitfalls and solutions for working with this population. The CBPR process we used highlights the critical importance of engaging Deaf people in all aspects of survey research if we are to collect reliable and valid information about Deaf seniors’ end-of-life care knowledge, attitudes, preferences, and experiences. A preliminary review of survey research with 130 Deaf senior citizens strongly indicates a desire for information about hospice and end-of-life care. It also strongly indicates the need to make this information available in ASL. We plan to continue our research efforts,

gathering data on a national sample of Deaf seniors, adding specific questions related to pain assessment issues.

NOTES

1. Following Padden and Humphreys, we use the lowercase *deaf* when referring to the audiological condition of not hearing, and the uppercase *Deaf* when referring to a particular group of Deaf people residing in the United States and Canada who share a culture, use sign language as their primary means of communication among themselves, and hold a set of beliefs about themselves and their connection to the larger society.
2. The Project conducted three focus groups in which participants viewed three closed-caption videotapes about end-of-life care. Participants unanimously agreed that the English language usage was an obstacle to their learning about healthcare information.
3. The study of signed languages and the field of Deaf education are disciplines filled with debate. The Deaf community may also be characterized by dissensus concerning various approaches to education. Here, we intend only to provide an overview of research findings that we considered in structuring our research. These findings were important to us, because they were consonant with the experience of the members of the Deaf community with whom we worked in designing and conducting this project.
4. These scales are among the pain assessment tools made available to palliative care providers on many websites, including *Partners Against Pain* as cited, <http://www.partnersagainstpain.com>, accessed 5/10/02 and the American Medical Directors Association, <http://www.amda.com/clinical/chronicpain/pain-face.html>, accessed 5/15/02. Although neither organization recommends the use of this scale in groups other than those intended by the Wong and Baker, it has increasingly been accepted for use with adults under palliative care.
5. Comparisons of various scales including the faces pain scale (FPS) (horizontal) numeric rating scale (NRS) given below, vertical visual analog scale (VAS), verbal numeric scale (VNS) and verbal descriptor scale (VDS) show that the age does not significantly affect the use of the FPS. Higher levels of pain were reported using the VNS and the VDS discriminated best between increasing intensities

of pain. The VAS was subject to higher failure rate, as was the NRS when administered repeatedly in short periods of time.

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