



Published in final edited form as:

*Palliat Med.* 2010 January ; 24(1): 88–93. doi:10.1177/0269216309348180.

## Challenges Facing a Deaf Family Member Concerning a Loved One's Dying

**Karen A. Kehl, PhD, RN, ACHPN** and

KL2 Scholar, Institute of Clinical and Translational Research, Post-doctoral Scholar, School of Nursing, University of Wisconsin-Madison

**Constance M. Gartner, MA**

Doctoral Student, School of Education, University of Wisconsin-Madison

Principal, Elementary School, Wisconsin School for the Deaf

### Abstract

Individuals who are Deaf face challenges both similar and unique from those faced by hearing individuals when a family member is dying. This study was guided by the question “What are the challenges faced by a Deaf family member when a loved one is dying?” Methods - This qualitative study is guided by critical theory and an interpretive perspective. Robert, a college-educated older adult who has been Deaf from birth was interviewed in American Sign Language using a death history format. Results – There are challenges for Deaf family members that affect communication with both the dying person and health care professionals. Patient-family communication issues included physical challenges and financial challenges. Lack of cultural competence concerning the Deaf community created challenges communicating with professionals. Decision-making was also a challenge.

**Conclusions**—These findings provide a framework for future research concerning the needs of Deaf individuals facing the end of life and provide guidance for clinicians.

### Keywords

deafness; death; family; communication

---

“It was hard to chat with him because he couldn't keep his eyes open.” – Robert

### Introduction

In recent years, studies of end-of-life care from the perspective of various ethnic and linguistic minorities have been conducted [1–3]. Yet, there little has been published concerning the experience of Deaf individuals in the United States when a loved one dies. This paper uses a case study to illustrate the challenges that Deaf family members face while a loved one is dying. Deaf (with a capital D) refers to those who identify socially and culturally with the Deaf community. American Sign Language (ASL) is the primary language of the Deaf community in the United States (U.S.) with other sign languages used in other countries such as Australian Sign Language (Auslan) in Australia or Israeli Sign Language (ISL) in Israel. Deaf community members include hearing relatives of Deaf individuals who communicate in sign language.

There is abundant data demonstrating that good communication is a vitally important issue to family members of a dying person [4–11]. When the primary language of the dying person or the family member is different than that of the health care team, additional concerns about communication are expected. Miscommunication concerning end-of-life issues in non-English speaking communities can create misunderstandings and conflict [12]. In studies describing the experience of Spanish speaking families in the U.S. and aboriginal peoples in Canada, concerns with language barriers have been raised including: 1) inaccurate translation, even when interpreters are available [2,3,13]; 2) limited access to healthcare facilities where interpreters or native speakers are available [3] and; 3) the use of family members as translators [2,3]. There is concern that those in non-dominant language groups may receive sub-standard care, either as a result of overt discrimination or as a result of lack of knowledge and/or understanding on the part of the patient, family or the healthcare professional due to language barriers.

Estimates of the size of the Deaf community range from 100,000 to 1.8 million in the U.S. alone [15]. ASL, the primary language of the U.S. Deaf community, is considered the third most commonly used language in the United States [14]. ASL is a visual language with its own grammar and syntax. It is not a variation of English and it has no written form. English is a second language for Deaf individuals and, when spoken, typically requires interpretation. Because ASL is a visual language, gestures, facial expressions, and the space surrounding a Deaf person all carry meaning.

In addition to being a linguistic minority, the Deaf community has a rich and vibrant culture. Additionally, the Deaf culture has social rules which might seem rude for those unfamiliar with its norms. For example, a common means of getting one's attention in the Deaf community include touching the person, stomping the foot, banging a fist on a table, or waving the hand in front of the face. These gestures may seem rude in the speaking community but are considered appropriate and even polite among the Deaf. Another cultural difference which affects healthcare communications is the variations in how words are interpreted. For example, the word "positive" in English has many meanings including good, positively charged, more than zero and present (as in "HIV positive"). In ASL "positive" is indicated by the forefingers making a "+" sign and indicates good or beneficial, or in a mathematical problem, plus. Barnett [16] points out the difficulties this can create when hearing healthcare professionals tell a Deaf patient that an HIV test is "positive". To the healthcare professional this indicates a serious health issue that needs to be addressed, but to the Deaf individual it means that the test was good and there is no problem, in other words, that they do NOT have the HIV virus. The Deaf person may understand this as good news whether it is communicated through speech reading (lip reading), note writing, or through an interpreter who is not experienced in healthcare interpretation.

There are well documented issues in English literacy [17,18] for Deaf individuals which affect the practice of using written English to communicate with Deaf family members. Deaf adults in the U.S. average below a fourth grade level (approximately age 9–10) on tests of reading ability [19] and less than 20% of adults in one study rated themselves as fluent in English [20].

There is limited research concerning health care for the Deaf community and even less regarding care at the end-of-life. Most of the research surrounding health care for Deaf individuals focuses on communication [21–24]. From this literature we know that most Deaf patients find that healthcare professionals communicate through written English (75.9–83.0%) or by speaking (54.5–58.5%) and only a small proportion (6.4–7.1%) used a sign language interpreter while only slight more (8.1–9.6%) used gestures [22]. A study in Minnesota, in which 130 Deaf adults were surveyed, demonstrated that, like other linguistic minorities, Deaf

people felt that lack of access to information in their language was a barrier that affected an individual's ability to understand one's illness and to make decisions about end-of-life care [25]. The authors of this study strongly suggest that communication about the decisions surrounding end-of-life care should be conducted in ASL. This recommendation was echoed in a recent report on cross-cultural considerations in end-of-life care in Canada. Deaf individuals interviewed for the Canadian report said: 1) The Deaf community needs more information about death, dying and palliative care; 2) Healthcare professionals need cultural awareness and competence training concerning the Deaf community; and 3) Final communications between an dying person and the family need to occur early since as the dying person weakens the ability to sign diminishes [26].

Given the challenges faced in cross-cultural communication for end-of-life care and the dearth of specific information about the needs of Deaf family members, we set out to further understand the challenges this community faces while a family member is dying. The question that guided this inquiry was, "What are the challenges faced by a Deaf family member when a loved one is dying?"

## Methods

This was a qualitative case study in which one participant, a college educated older Deaf male, was interviewed about the challenges he faced interacting with the health care system as three of his loved ones were dying. Approval for the study was received from the Social Sciences institutional review board at the University of Wisconsin-Madison.

## Participant

The participant was solicited by placing a poster up in the state residential Deaf school seeking participants. Criteria for inclusion included self-identifying as Deaf, being able to communicate in ASL and/or English, and having experienced the death of a family member. Robert volunteered and we chose to interview him based on his high literacy level and his openness to discuss the subject.

A death history interview was conducted. Death history interviews are a technique used to outline a person's previous experiences with death and to describe their feelings and reactions to the deaths they have experienced [27,28] (See sample questions in Table1). The interview was conducted by C.G., a hearing woman proficient in ASL, via videophone, a device that broadcasts live images over a broadband network. Videophone was chosen because: 1) It is a technology that is familiar and comfortable to most Deaf individuals, 2) It allowed the interview to be conducted in ASL, the participant's primary language, and 3) It allowed video recording of both the interviewer and the participant. The interview was video recorded and later transcribed and translated into written English. We purposefully kept the interview style open-ended in order to elicit the participant's memorable death experiences. The interview lasted about 90 minutes and was concluded when the participant indicated that he did not have anything else to add about his experiences with death.

## Trustworthiness

We began addressing trustworthiness prior to conducting the interview by having potential interview questions reviewed by a certified ASL interpreter who verified that C.G.'s ASL interpretation of the questions was culturally and linguistically appropriate. During the interpretation and transcribing of the interview, any sections that were unclear were reviewed and verified by a second certified ASL interpreter. Finally, the participant was invited to review the written English transcript or to have the written transcript translated back into ASL to verify

that we had accurately captured the meaning. Robert chose to read the English transcript and he did not identify any errors in the transcript or our interpretation.

## Analysis

A content analysis using the continuous comparative inductive analysis method was used [29]. We followed a three-step method of qualitative code development and thematic analysis [30]: 1) Open coding in which each researcher reviewed the transcripts several times and coded the findings independently line by line; 2) Axial coding, in which the researchers developed categories based on the relationship of the codes; and 3) Thematic development in which themes were developed to represent broader conceptual categories and the clusters of codes [31].

## Results

### Participant Characteristics

Robert, a male in his 70s who has been Deaf from birth, attended a residential Deaf school as a child, went on to receive a teaching degree at Gallaudet University, and has taught at residential Deaf schools as an adult. Robert knew the interviewer (C.G.) in her role as principal of the Deaf school since he had served as a substitute teacher. We had previously conducted a similar interview with a participant who was not literate in English, and found that since the consent had to be translated into ASL, there were questions about her clear understanding of the concepts of informed consent which made use of the data questionable. In addition, Deaf individuals with low English literacy often have low ASL literacy [19], and we found that was the case with our previous participant. Our previous interview gave sketchy data about the circumstances of family member's deaths and virtually no information about the role played by the participant or the participant's feelings.

### Robert's Death Histories

Robert discussed three different death experiences, that of his mother, a Deaf friend whom he knew from childhood until death, and his son. Robert's mother and son were hearing. Robert's mother and friend died after long illnesses requiring hospital and skilled nursing facility care. Robert's son, who was a hearing adult married to a hearing woman, died of cancer.

### Communication Barriers are Challenges While a Loved One is Dying

In the course of telling us about the deaths of his loved ones, Robert described the difficulties he experienced with communication. There were both barriers to communication between Robert and his loved ones and between Robert and the healthcare professionals. Three types of communication barriers were described; physical, financial, and the cultural competence of others. Both physical and financial barriers affected Robert's communication with loved ones, and financial and cultural competence issues affected his communication with healthcare professionals.

### Physical barriers

Robert told us about how his son's sleepiness and inability to keep his eyes open in his final days altered communication.

“He could hear fine, but his eyes kept closing. It was hard to chat with him because he couldn't keep his eyes open...Of course, I wish that they had hired an interpreter so I could have communicated directly to him when his eyes were closed...”

Robert also explained how frustrated his childhood friend became as he developed arthritis in his hands hindering his attempts at communication.

### Financial barriers

Robert frequently commented that it would have been helpful to have an interpreter; at the nursing home when he visited his mother, at his dying son's bedside so he could communicate with him and at the hospital when meeting with doctors about his mother's healthcare. Robert was very aware of the cost of hiring an interpreter and more than once said that he would have asked, but he did not know who would pay for it. He talked about how Medicare and insurance paid all of his mother's medical expenses, but Medicare did not offer to pay for an interpreter for him to understand what the doctors were saying about her condition or for him to communicate with his mother.

### Cultural competence of others

We came to understand that hearing individuals do not often understand that ASL, not English, is the primary language of the Deaf community. Robert explained that communication in ASL was not offered to him. Written English was used frequently by healthcare professionals for communication. Health care professionals found this an acceptable means of communication with Robert. Robert told us of how he wrote things down for the nurse to speak to his son.

Robert is very well educated and has a good understanding of written English. Despite this, he found it burdensome to have all communication with the doctors and the nurses in written English. About his mother's stay in the skilled nursing facility Robert said,

“I want to tell you that I had a hard time communicating with the nurses there. Nice people, but we had to write back and forth to communicate.”

One of the highlights in Robert's memory is his son's funeral. To include Robert and his Deaf wife, his son's wife hired an ASL interpreter and used visual presentations.

“It was beautiful. It was wonderful. It was a beautiful service. They showed pictures during that ceremony. It was nice.”

### Decision-making

Robert was actively involved in healthcare decision-making for his mother and he described how his opinion was solicited. He explained that he formally met with his mother's medical team only once despite the fact that he went to visit his mother almost every day.

“The doctors and nurses got together to meet with me. And there was no interpreter, so we had to write back and forth. But they told me that Mom was not eating well, that she wasn't taking her medicine, they were having a hard time with her and they asked me what to do. They wanted my opinion. I told them I would support whatever their decision was.”

Robert thought that he was in charge of decision-making for his mother, even though he deferred to the opinion of the healthcare team and his hearing brother's wishes.

“My brother let me make all the decisions. He stayed in California. As time went on and we needed to keep transporting her back and forth to the hospital, my brother came to visit and asked why we were prolonging her life. She had no quality of life. (He said) We should just let her go. I was upset by that, but I realized that he was right.”

### Discussion

Robert's stories highlight many of the issues that have been raised in previous research about family members' experiences and concerns while a loved one is dying. His stories echo concerns related in the research findings about the experiences at the end-of-life of English

and non-English speaking family members (see Table 2). However some unique challenges were identified as well.

Robert raised our awareness of the physical barriers that exist for a Deaf person who is trying to communicate with someone who is dying. Other researchers have reported that physical barriers to communication such as the patient having an endotracheal tube, which makes verbal communication impossible, are very distressing to family members [32]. This raises clinical questions about offering options for care that might increase wakefulness and minimize visual side effects for those who use manual communication. Clinicians need to be aware of patients who use manual communication when they order or implement use of devices such as IVs and restraints that limit movement and make manual communication impossible.

Another challenge to communication was the lack of an interpreter. Robert was acutely aware of the cost of an interpreter and could not offer to pay it himself, nor did he want to burden healthcare agencies with the expense, even though in the U.S. they have a legal obligation to provide an interpreter [33]. Many physicians in the U.S. do not offer an interpreter since the cost exceeds their reimbursement for the visit [34]. The Americans with Disabilities Act (ADA) prohibits discrimination against individuals with disabilities by places with public accommodations, including all health care settings. The ADA requirements include interpreter services for family members who are involved in the ill person's care [24] including decision-making. Many healthcare organizations meet this ADA requirement by providing a telecommunication device for the Deaf, commonly known as a TDD or TTY. To use a TTY the Deaf person must be able to read and write English so they can type their responses. A hearing operator speaks the message to the hearing party, listens to the spoken response and types it so the Deaf party can see it in text. Recently, some hospitals have begun using videophones to connect with ASL interpreters when dealing with Deaf patients [35]. For us, the fact that interpreters were not offered to Robert raised questions about ways to provide communication in a manner that is as close to that preferred by the Deaf person as is possible. With web cam technology, which is inexpensive and easy to set up, an interpreting service for healthcare institutions could be created that would allow the Deaf person to sign via a webcam to an interpreter who could translate into spoken English. This interpreter could then interpret the spoken responses of healthcare professionals into ASL, which could be seen on-screen by the Deaf person. This imitates videophone technology but at a much lower cost to the institution.

There is a need for additional research to further explore the themes identified by Robert and to explore issues such as the role of non-healthcare professionals at the end-of-life (e.g. attorneys and funeral directors) and how these professionals interact with Deaf family members. From this case study one cannot say if the passive role that Robert played in end-of-life decision-making was related to his personal preferences, family preferences, or difficulties in understanding due to the language barrier. Future research needs to explore issues of decision-making at the end of life when the patient or family is Deaf, including how the Deaf person gets information and who ultimately makes the decisions.

There are some significant challenges to conducting research in the Deaf community. We recommend working with someone who can serve as a guide to the community. This can make it easier to access Deaf individuals willing to participate and ensure that the interviews are culturally sensitive and precise enough for the needs of the researchers. In addition to having an interpreter to conduct or interpret the interviews, a second interpreter should be used to verify the accuracy of the interpretation and transcription into English.

The Deaf community is a minority group that is often overlooked and underserved, especially concerning healthcare. Robert's experiences provide a springboard for future inquiry about the



experiences of Deaf individuals at the end of life and provide guidance for clinicians. Attention to details such as maximizing mobility of the hands and obtaining competent interpreters when direct communication is no longer possible or when communicating to Deaf family will help ensure that Deaf people and their families can receive the very best care at the end of their lives.

## Acknowledgments

The authors would like to acknowledge Clifford Conrad for his guidance in methods and editing this manuscript. Dr. Kehl was supported by grant 1UL1RR025011 from the Clinical and Translational Science Award (CTSA) program of the National Center for Research Resources, National Institutes of Health during this project.

## References

1. Colon M. Hospice and Latinos: a review of the literature. *J Soc Work End Life Palliat Care* 2005;1(2): 27–43. [PubMed: 17387062]
2. Kelly L, Minty A. End-of-life issues for aboriginal patients: a literature review. *Can Fam Physician* 2007;53(9):1459–1465. [PubMed: 17872874]
3. Sullivan MC. Lost in translation: how Latinos view end-of-life care. *Plast Surg Nurs* 2001;21(2):90–91. [PubMed: 12025132]
4. Hanson LC, Danis M, Garrett J. What is wrong with end-of-life care? Opinions of bereaved family members. *Journal of American Geriatric Society* 1997;45(11):1339–1344.
5. Kehl, K., et al. Challenges facing families at the end of life in three settings. Madison, WI: University of Wisconsin-Madison; 2007.
6. Baker LM. Information needs at the end of life: a content analysis of one person's story. *J Med Libr Assoc* 2004;92(1):78–82. [PubMed: 14762466]
7. Tong E, et al. What is a good death? Minority and non-minority perspectives. *Journal of Palliative Care* 2003;19(3):168–175. [PubMed: 14606328]
8. Vohra JU, et al. Family Perceptions of End-of-Life Care in long-term care facilities. *J Palliat Care* 2004;20(4):297–302. [PubMed: 15690832]
9. Steele LL, et al. Patient and caregiver satisfaction with end-of-life care: does high satisfaction mean high quality of care? *American Journal of Hospice & Palliative Care* 2002;19(1):19–27. [PubMed: 12171422]
10. Teno JM, et al. Family perspectives on end-of-life care at the last place of care. *Journal of the American Medical Association* 2004;291(1):88–93. [PubMed: 14709580]
11. Steinhauser KE, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. *Journal of the American Medical Association* 2000;284(19):2476–2482. [PubMed: 11074777]
12. Hallenbeck JL. Intercultural differences and communication at the end of life. *Primary Care; Clinics in Office Practice* 2001;28(2):401–413.
13. Born W, et al. Knowledge, attitudes, and beliefs about end-of-life care among inner-city African Americans and Latinos. *J Palliat Med* 2004;7(2):247–256. [PubMed: 15130202]
14. Lotke M. She Won't Look at Me. *Ann Intern Med* 1995;123(1):54–57. [PubMed: 7762915]
15. Barnett S. Clinical and cultural issues in caring for deaf people. *Fam Med* 1999;31(1):17–22. [PubMed: 9987607]
16. Barnett S. Cross-cultural communication with patients who use American Sign Language. *Fam Med* 2002;34(5):376–382. [PubMed: 12038720]
17. Erting C. Deafness and literacy: Why can't Sam read? *Sign Language Studies* 1992;75:97–112.
18. Paul PV. Deafness and text-based literacy. *Am Ann Deaf* 1993;138(2):72–75. [PubMed: 8498274]
19. Strong M, Prinz P. A study of the relationship between American sign language and English literacy. *J Deaf Stud Deaf Educ* 1997;2(1):37–46. [PubMed: 15579834]
20. MacKinney TG, et al. Improvements in preventive care and communication for deaf patients: results of a novel primary health care program. *J Gen Intern Med* 1995;10(3):133–137. [PubMed: 7769469]

21. McEwen E, Anton-Culver H. The medical communication of deaf patients. *J Fam Pract* 1988;26(3): 289–291. [PubMed: 3346631]
22. Schein J, Delk M. Survey of health care for deaf people. *The Deaf American* 1980;32:5–6. 27.
23. Ebert DA, Heckerling PS. Communication with deaf patients. Knowledge, beliefs, and practices of physicians. *JAMA* 1995;273(3):227–229. [PubMed: 7807662]
24. Steinberg AG, et al. POPULATIONS AT RISK: Health Care System Accessibility. *JGIM: Journal of General Internal Medicine* 2006;21(3):260–266.
25. Allen B, et al. American Sign Language and end-of-life care: research in the deaf community. *HEC Forum* 2002;14(3):197–208. [PubMed: 12405039]
26. Con, A. Cross-cultural considerations in promoting advance care planning in Canada. Health Canada: Vancouver, British Columbia; 2007. p. 128
27. Davis, CM. Communicating with the dying and their families. In: Davis, CM., editor. *Patient Practitioner Interaction*. Slack, Inc.; 2005.
28. Worden, WJ.; Proctor, W. A personal death awareness. [cited 2009 April 1, 2009]. Available from: <http://74.125.95.132/search?q=cache:6t53uPl8gvIJ:www.tarleton.edu/~landerson/DEATH%2520S09/FINAL%2520PERSONAL%2520DEATH%2520AWARENESS.S09.doc+%22personal+death+history%22&cd=2&hl=en&ct=clnk&gl=us&client=firefox-a>
29. Conrad, C.; Serlin, RC. *The Sage handbook for research in education : engaging ideas and enriching inquiry*. Vol. xxii. Thousand Oaks: Sage Publications; 2006. 598 p.
30. Boyatzis, RE. *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, CA: Sage Publications; 1998. p. 200
31. Coffey, AJ.; Atkinson, PA. *Making sense of qualitative data: Complementary research strategies*. Thousand Oaks, CA: Sage Publications; 1996.
32. Kirchoff, KT.; Kehl, K. *State of the Science in Nursing Research*. Washington, D.C.: Council for the Advancement of Nursing Science; 2004. Family perceptions of care at the end of life in an ICU and hospice facility.
33. National Association of the Deaf. *ADA Questions and Answers for Health Care Providers*. 2008 [cited 2008 3/5/2008]. Available from: <http://www.nad.org/site/pp.asp?c=foINKQMBF&b=138000>
34. Nattinger AB. Communicating with deaf patients. *JAMA* 1995;274(10):795. [PubMed: 7650795]
35. Schlesinger, A. *USA Today*. 2004. Hospitals, deaf patients connect with video phones.



**Table 1**

## Sample Death History Questions

Main questions	Probes
What is the first death that you can remember? Who was it? How old were you? What do you remember? What was your role?	What did you do? How did you handle that? Tell me more about that? How did you feel about that?
What other deaths have influenced you? How?	
Is there one situation in which a friend or family member was dying that stands out in your memory? Why is it memorable?	

**Table 2**

Barriers to communication at the end of life

	<b>General literature</b>	<b>Literature concerning Non-English speaking family members</b>	<b>Robert's interview</b>
Healthcare professionals	Access to health care	Access (Language)	Access (Language)
	Understanding	Understanding	
		Cultural competence	Cultural competence
Both healthcare professionals and dying person			Financial barriers to obtaining interpreters
Dying person	Physical barriers		Physical barriers