

Palliative and End-of-Life Care in Newfoundland's Deaf Community

Victor Maddalena,

Faculty of Medicine, Division of Community Health and Humanities, Health Sciences Centre, Memorial University of Newfoundland, 300 Prince Philip Drive Room 2849, St. John's, Newfoundland and Labrador, Canada A1B 3V6

Fiona O'Shea, and

Dr. H. Bliss Murphy Cancer Centre, and Discipline of Oncology, Memorial University of Newfoundland, St. John's, Newfoundland and Labrador, Canada

Myles Murphy

Newfoundland and Labrador Association of the Deaf, St. John's, Newfoundland and Labrador, Canada

Abstract

The Deaf community is a distinct cultural and linguistic community (the uppercase *D* is a cultural identification). Compared to the general population, the Deaf community, as a social group, experiences poorer health status. Deaf people seek care less frequently than the general population and have fewer interactions with the health system. Their encounters with the health system are often characterized by communication difficulties, fear, mistrust, and frustration. Qualitative research was used to explore the experiences of family caregivers who provided end-of-life care for a Deaf person. Key findings indicate that the Deaf community has limited understanding of their options for palliative and end-of-life care. Communication and health literacy are key barriers to accessing appropriate end-of-life care. Pain and symptom management, consideration of physical environments, and limited access to bereavement care are common issues faced by Deaf people when caring for loved ones at the end of life.

Keywords

deaf; palliative care; end of life

INTRODUCTION

The Deaf community is a unique linguistic and cultural community (the uppercase *D* is a cultural identification). Compared to the general population, however, the Deaf community, as a social group, has a poorer health status (1,2) — mental health, in particular (3). It also has lower levels of employment (4), education, and English literacy, as well as a poorer socio-economic status (5). Deaf people have fewer interactions with the health system. They

seek care less frequently (1), and their encounters with the health system are often characterized by communication difficulties, fear, mistrust, and frustration (6, 7). Considering that the key determinants of health include income and social status, employment and working conditions, access to health services, and education and literacy (8), we can see that many Deaf people are vulnerable — that is, at an increased relative risk of adverse health outcomes (9).

Terminal illness, dying, death, and bereavement are experienced within a cultural context. There is a limited body of research that examines the experiences of Deaf people and their interactions with the health system, especially in the Canadian context; and there is a dearth of research examining palliative and end-of-life care issues in the Deaf community (10,11).

In this study, we used qualitative research methods and asked this research question: “What are the experiences of Deaf people living in Newfoundland regarding end-of-life and palliative care services?” Our research objectives were: to explore and describe the experiences of Deaf people at the end of life and the experiences of their caregivers; and to explore the institutional and cultural barriers that influence Deaf people’s decision to access, or not to access, the health care system during terminal illness — in particular, palliative care services.¹

THE DEAF COMMUNITY AND CULTURAL IDENTIFICATION

The common understanding of deafness is that it is hearing impairment experienced to the extent that it interferes with the normal activities of daily living. The spectrum of hearing loss ranges from hard of hearing to profoundly deaf (12). Using the uppercase *D* for “Deaf” acknowledges the cultural identification of the Deaf community. An important feature of self-identifying with Deaf culture is using American Sign Language (ASL) as one’s predominant means of communication. We acknowledge that many issues experienced by the Deaf, deafened and hard of hearing may be similar, but in this study we limit our examination to the experiences of the Deaf community. It is important to understand that among Deaf people, deafness is not perceived as a disability (5, 12, 13, 7).

ASL is a non-verbal, gestural language. It is recognized as a distinct language with its own structure, idioms, grammar, and syntax. It is defined as “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” (10, p. 200). Like spoken languages, ASL and other signed languages have local and regional dialects. Margellos-Anast and colleagues state that in terms of English literacy skills, the average reading level for someone prelingually Deaf is the fourth grade, and thus many Deaf people also experience difficulties with written language (14).

¹We have also developed a video, *Palliative Care Guide for the Deaf Community*, to provide information, in sign language, on various aspects of terminal illness, palliative care, and death that Deaf people and their caregivers may encounter. The video is available on YouTube under the search heading “deaf palliative care.”

THE DEMOGRAPHICS OF NEWFOUNDLAND AND LABRADOR'S DEAF COMMUNITY

In Canada, approximately 1.2 million people aged 15 and over (approximately 5 percent of the national population) report a hearing limitation. Of those who reported a hearing limitation, 83.2 percent described a mild hearing loss, and 16.8 percent described a severe one (15). In the opinion of the Canadian Association of the Deaf, Canada has never conducted a credible census of Deaf, deafened, and hard-of-hearing people (16). Personal communications with representatives of the Newfoundland and Labrador Association of the Deaf (NLAD) suggest that there are approximately 500 people who self-identify as Deaf in the province; of these, 150 to 200 live in the Northeast Avalon Region, which encompasses the capital, St. John's, and surrounding communities (with a population of 192,326, out of a provincial population of 509,200) (17, 18). Newfoundland and Labrador is Canada's most easterly province.

LITERATURE REVIEW

There are a limited number of studies examining health services and the Deaf community in the Canadian context. While a number of studies examine the doctor-patient dynamic (most often focusing on communication issues) (5, 12, 19–21), fewer look at issues related to accessing and utilizing health services (22, 23). Most of these studies have originated in the United States, and because US health insurance models have no parallel in the Canadian system, their findings cannot be generalized to the Canadian setting.

Literature examining end-of-life care issues in the Deaf community is limited. Kehl and Gartner (11) conducted a qualitative study using a death-history format with a key informant who was Deaf. They identified as prominent concerns: communication difficulties, physical challenges, financial barriers associated with hiring interpreters, a lack of cultural competence among health providers, and decision-making challenges.

The population health literature on the health status of Deaf Americans suggests a relationship between social exclusion, limited educational and employment opportunities, limited access to health services, and poor health status similar to that which is experienced by other minority groups (5, 24–30). This relationship also exists for Deaf Canadians.

Limited access to health services, and the resultant poorer health status of the Deaf population, are believed to be related to language barriers, limited literacy skills, limited access to health practitioners fluent in ASL, and limited education and employment opportunities (5, 7).

Moreover, Margellos-Anast and colleagues also found that many Deaf people are unfamiliar with medical terminology and basic health information (14).

METHODS

This research was approved by the Human Investigations Committee (HIC) of Memorial University of Newfoundland. The interview data was collected in 2009 and 2010. The

project used qualitative research methods — specifically, the paradigms of naturalistic inquiry and participatory research methods. A naturalistic approach to research is based on the social constructivist belief that there are multiple realities shaped by both the researcher and the participant, and that these shared realities are influenced by the social and political context (31–33).

Our research also incorporated elements of participatory research, which has two main features: shared development and ownership of the research project (including defining the research questions, determining research methods, and analyzing data); and the use of research findings to influence change (33). This study was designed and implemented in collaboration with the NLAD.

Preparation of Informed Consent

English is not the first language of many Deaf people, and others may have low levels of English literacy. We approached the consent process with the prior experience of Margellos-Anast and colleagues (14) in mind, as well as advice we received from the research office at Gallaudet University in Washington, DC, USA.²

We began by preparing a consent form that was acceptable to the HIC. The form was then reviewed by a trained ASL interpreter and a Deaf interpreter³ who ensured that it had been translated appropriately into ASL specific to Newfoundland and Labrador without losing the intended meaning of the consent as required by the HIC. Two versions of the consent were then prepared — one in written English, and one in ASL in video format. Potential research participants were offered a printed consent form in English and/or a DVD that translated the form into ASL. All participants were given the opportunity to ask the researcher questions before signing the consent form. A DVD version of the informed consent and a copy of the print version were given to each participant.

Participant Selection

We used two sampling techniques to select study participants: purposive sampling and snowball sampling. Purposive sampling involves selecting research participants based on characteristics of interest to the research (34); with snowball sampling, participants identify other potential participants (35). Participants who met certain inclusion criteria were invited to participate. All were: self-identified members of the Deaf community, residents of the Northeast Avalon Region, 19 years of age or older, and the caregiver of a Deaf person who had died.

The Deaf community is relatively small, and social networks are close, so communicating with members of the community about the research was relatively straightforward. If an individual agreed to participate, then the formal informed consent process was initiated. Potential research participants were not approached by individuals whom they did not know.

²Telephone conversation with Sally Dunn, Office of Research, Gallaudet University, Washington, DC, USA, August 21, 2008.

³A Deaf interpreter (DI) is a Deaf person who interprets for the Deaf. DIs are very skilled in ASL. They communicate information to Deaf people by taking simple and complex concepts from one language and faithfully (both linguistically and culturally) rendering the message in the target language (ASL). DIs usually work with hearing interpreters.

Seven who met the inclusion criteria agreed to participate in the research project: four men and three women, ranging in age from 40 to 65. (To protect the identities of participants, we will not provide further demographic information.)

DATA COLLECTION AND ANALYSIS

Our team approached this study with the understanding that qualitative research would be used to interpret phenomena, make sense of the world, and communicate a story (36). Participants shared their experiences with us and we, in turn, reflexively interpreted this experience.

All the interviews were conducted in ASL and videotaped. The videos were viewed by an ASL interpreter, translated (from ASL to English), audiotaped, and transcribed verbatim. The research team coded the transcripts manually for prevalent themes and unique narratives. A team meeting was held to discuss team members' individual coding. We did not engage in any structured, formal analysis of the video data.

Transcribed audio data were analyzed using thematic and discourse analysis (37). We understand discourse analysis to be based on the belief that language in the form of text or narrative (or, in this case, sign language) communicates meaning, and these data can be analyzed (38). The researchers possessed insider knowledge of (39), and familiarity with, Deaf culture, and this knowledge and familiarity figured prominently in all stages of the research process.

In our interviews, we explored three areas: participants' experiences and perceptions of accessing and utilizing health services, particularly palliative care services; their perception of the barriers they encountered in accessing culturally appropriate health services; and their notion of what would constitute culturally competent health care for the Deaf at the end of life. We also examined issues related to accessing and utilizing various health services, patient decision making, language and communication, and the role of family and community.

We identified a number of themes, including: participants' limited experience with death; participants' limited knowledge of available palliative care services; limited knowledge of Deaf culture on the part of health professionals; communication problems between the Deaf and health professionals; the roles of family and community caregivers; the physical environment of the Deaf; symptom management; and limited access to post-death support. These themes are discussed individually in the next section.

RESULTS

Limited Experience with Death

Study participants reported that they had limited experience with death. Many Deaf people feel isolated from the hearing community, and even from their own hearing family members. Participants described situations in which family members were terminally ill and expressed that they felt excluded from family discussions about diagnosis, prognosis, and treatment

options. They felt marginalized in terms of family decision making; they were often left out of discussions between family members and health professionals.⁴

“I didn’t have an interpreter, and I felt really left out, and I didn’t know what ‘palliative care’ meant, and they said they would move him to the [palliative care unit], and I was like, ‘What do you mean?’ I didn’t know what was going on.”

Participants also expressed uncertainty and discomfort about not knowing how to react to a dying patient, especially when the patient was Deaf.

“I was like, ‘How is [communication with a Deaf person] going to work?’ — you know, and the communication was difficult. How do you talk to someone who is dying who is Deaf? How do you let them know they are there if they are, you know, not opening their eyes and are not communicative?”

One participant responded to the interviewer’s question about the way in which Deaf culture faces death by explaining:

“With the Deaf group, when they got together and someone was dying, it was a different experience. It was very sad. It was very serious. There were no stories. People were quiet, and I noticed it. It’s like, culturally, they don’t know how to express it.”

Limited Knowledge of Available Palliative Care Services

In ASL, there is no specific sign for “palliative care.” In conversation, the words would initially be spelled out using finger spelling, and then the term would be described in sign as “comfort care as a person approaches death.” In our study, knowledge of palliative care, its meanings, and the services associated with it varied among individuals. In general, participants expressed that they had limited knowledge of palliative care services.

Participants were also generally unaware of the options for location of death: in home or in hospital. They believed that when their loved one’s illness progressed, or when that person’s death was imminent, hospital admission was expected.

“Maybe some people prefer to stay home, but I think the Deaf don’t realize they have the choice to stay at home or go to the hospital or the palliative care unit. I think hearing people assume that Deaf people will know these options.”

Limited Knowledge of Deaf Culture on the Part of Health Professionals

The Deaf participants in this study expressed the need for health professionals to learn more about Deaf culture, including how to communicate effectively with Deaf people.

“Really, the hospital doesn’t know what to do with a Deaf person. They assume that the Deaf person already knows everything, and I think that is not true.”

Deaf people may also have limited exposure to illness and death and may not be familiar with health services norms.

⁴All of the following quotations of study participants are presented as the English translation of the ASL interview.

Communication Problems between the Deaf and Health Professionals

Communication is the most significant issue affecting the quality of care for Deaf people. Since health professionals are generally incapable of communicating effectively in ASL, trained ASL interpreters are required to facilitate the care-provider/ patient relationship. Even in urban centres, it is very difficult to find ASL interpreters after hours or on weekends. There are a limited number of trained interpreters, and 24/7 coverage is not always possible. In the following dialogue between a participant and the interviewer, the Deaf participant describes bringing their Deaf friend to the hospital late at night and discovering that no interpreter was available.

Participant: *“We went to the hospital. There was no interpreter there. With the nurse, we were writing back and forth.”*

Interviewer: *“Why was there no interpreter?”*

Participant: *“Well, it was late at night...probably midnight [or] later when we got there.”*

Interviewer: *“Did you tell the hospital that you needed an interpreter?”*

Participant: *“Yes, but we had to wait for an interpreter. We waited for a long time, and nobody came.”*

In rural and remote areas, where there are few Deaf people and interpreters, it may be impossible to provide interpreter services. While many Deaf people must rely on family members or close friends to serve as interpreters (or else write notes back and forth), they find these methods of communication to be less than ideal. For some, however, having a trusted hearing family member serve as interpreter is acceptable — indeed, preferable.

There is considerable diversity among Deaf people in terms of their ASL fluency. Some use a combination of communication methods, including finger spelling, ASL, and miming. Those who became Deaf later in life may have good verbal language skills, but verbal communication is only one aspect of overall communication. While many Deaf people can lip-read well enough to engage in casual conversation, most understand that it is not a reliable form of communication. It is often easier for a Deaf person to agree than to struggle to communicate.

When a qualified ASL interpreter is required, but not available, the Deaf person who needs an interpreter may feel anxious. One participant reports on an emergency room visit during which such a situation arose.

“I mean, it is a Deaf person’s right to have an interpreter...and most do use an interpreter, but the one concern about it is the time delay to get the interpreter and then to get the communication going.”

Also, the English language is filled with idioms that are often not well understood by Deaf people. Interpreting medical terminology can be difficult, as well, because much of this terminology has no ASL sign and so must be explained using simple language. As noted earlier, Deaf people possess varying degrees of English literacy. It is important for health professionals to be aware of this when they are communicating in writing with Deaf people

or providing them with printed material. Health professionals should not assume that because a Deaf person nods “yes,” he or she has understood.

In the Deaf population, English literacy and ASL fluency are often dependent upon age and geography (urban or rural). Elderly Deaf people may have lower levels of English literacy and may rely on older forms of signed communication, such as Old English Sign Language, two-handed finger spelling, minimal sign language, or miming.

The Roles of Family and Community Caregivers

Among Deaf people, the concept of “family” encompasses biological family, friends, and community. The Deaf community is a close-knit social network whose members are interdependent and support each other.

The Physical Environment of the Deaf

Deaf people live in a visual world. It is therefore paramount to consider the physical environment of Deaf people who are terminally ill. For example, palliative care settings typically have subdued lighting, but this makes ASL communication difficult. Most Deaf people prefer full lighting to facilitate communication.

“The Deaf people would come, and [the lighting] was very dim. I remember we had to be close to each other. We were sitting close and trying to sign, but to continue to do it for a long time was hard...we’d go out in the hallway where it was bright.”

Moreover, Deaf people who are asleep or comatose are completely cut off from communication.

“With a Deaf person, once their eyes are closed, the world is shut out.”

For a Deaf person, touch is a vital source of comfort and communication. How and where a Deaf person is touched has meaning. For example, it is considered inappropriate to touch a Deaf person’s head.

Symptom Management

Physicians and nurses responsible for caring for Deaf patients need to communicate effectively, through an interpreter, with these patients and their caregivers in order to treat the patient’s symptoms. In such instances, visual aids to assess pain can be helpful; one such aid is the Wong-Baker FACES Pain Rating Scale (40). Common descriptors of pain — such as “stabbing,” “throbbing,” “dull,” or “sharp” — are not helpful, as Deaf people do not typically characterize pain in this manner. It is easier for them to communicate the intensity and location of their pain.

“Deaf have a really hard time explaining what kind of pain they have...for example, stabbing — they ask if it’s a stabbing pain, and the Deaf person is, like, ‘Stabbing?’ Pain doesn’t look like stabbing. It doesn’t look like pinching. It’s really hard to get a Deaf person to explain the feeling for the word.”

Health professionals must not assume that Deaf patients and their Deaf caregivers have understood their explanation of the available options for pain and symptom management.

Clinicians should carefully discuss (preferably with the aid of an interpreter) with caregivers and patients the patient's pain and symptoms before establishing a management plan.

Limited Access to Post-death Support

It is difficult for Deaf caregivers to access bereavement support, as grief support groups and one-on-one grief counselling are typically designed for hearing people. This does not preclude Deaf people from benefiting from such support. They can do so with the assistance of an interpreter, but this makes sharing personal feelings more challenging.

“[Grief support groups are] really not a whole lot of a benefit for Deaf people because they feel like they're surrounded by hearing people, and they're the ones left out, so they don't really talk a lot. They feel like people are looking at them oddly. They're not comfortable.”

Most Deaf people feel isolated from the hearing community and receive supportive care and comfort from family or community members. Participants in this study acknowledged that sharing their feelings on the subject of death is uncomfortable for them.

DISCUSSION

Facing a terminal illness is a particularly challenging life experience for Deaf people and their families. Deaf people are more vulnerable to adverse outcomes because they face unique challenges — specifically, health care providers who cannot communicate in sign language and who lack an understanding of Deaf culture. Participants in this study related their stories and experiences of caring for a Deaf loved one at the end of his or her life. Our intention was not to provide information that could be generalized to apply to all Deaf people, but rather to present the views of those who participated in the study. The sample size for the study was relatively small, and yet there was remarkable consistency in the experiences of our respondents.

Communication is a central feature of any effective care-provider/patient relationship. Paramount among our findings is that our participants felt that health care professionals must take into particular consideration the fact that Deaf patients and their Deaf caregivers communicate through sign language. This means that the services of trained ASL interpreters are needed in health care settings, as are other forms of visual communication; however, it is difficult to access ASL interpreters in non-urban settings, at night, and on weekends. Moreover, health professionals must recognize that Deaf people have varying levels of ASL fluency, and thus a personalized approach to communication is needed.

Many Deaf people live in isolation, separate from the hearing community. Thus, another study finding was that study participants had limited knowledge of the services, treatment and symptom management options, and options for location of death (at home or in hospital) available to them; this, too, could have an adverse impact the end-of-life journey of terminally ill Deaf people. Also, Deaf caregivers and family members lack appropriate access to bereavement support after the death of a loved one.

RECOMMENDATIONS

As we stated earlier, attention needs to be given to effective communication so that health professionals can properly assess and attend to the palliative care needs of Deaf patients and their families. Access to the services of trained ASL interpreters is essential; in areas where they are not available, alternatives such as video-conferencing should be considered. Open and frank discussion between health professionals and Deaf patients and caregivers — about diagnosis, prognosis, the likely course of the disease, treatment options, pain and symptom management, and location of death — is very important. In order to undertake this successfully, health professionals must determine the health literacy level of both patient and caregiver and select the most effective means of communication based on this determination.

It is important for health professionals to develop relationships with their Deaf patients (as it is with their hearing patients) and to get to know these patients as whole people, with individual likes and dislikes, unique family situations and personal histories. Being admitted to hospital can be a bewildering experience for a Deaf person. It is especially important that the health professionals and support staff they will encounter during their hospital stay (or home support workers) are identified for them. Deaf patients need to know the names of these people, their functions, and the ways in which they will be involved in the care process. Maintaining caregiver consistency will comfort Deaf patients and reduce their anxiety.

There are many opportunities for further research in the area of palliative and end-of-life care for the Deaf community. Areas in which more work needs to be done include:

- Modifying palliative care assessment tools, pain management tools, nursing care plans, and outcome measures to address the specific health needs of Deaf people.
- Developing culturally relevant bereavement care programs for Deaf caregivers and family members.
- Improving access to ASL interpreter services, particularly in rural and remote areas, as well as finding innovative ways to use technology, such as video-conferencing, to communicate with Deaf patients and caregivers.
- Examining ways in which to enhance the physical environment of the palliative care unit to accommodate and support Deaf patients, who live in a visual world, and who therefore require, for example, sufficient lighting to communicate in sign language.
- Determining how palliative care services can support the needs of Deaf patients who choose to die at home, as well as the needs of their families.

Acknowledgments

This research was funded by a Newfoundland and Labrador Centre for Applied Health Research (NLCAHR) Healthy Aging Research Program seed grant. Special thanks to ASL interpreter Sheila Keats, and to the NLAD for its support.

References

1. Barnett S, Franks P. Health care utilization and adults who are deaf: relationship with age at onset of deafness. *Health Serv Res.* 2002; 37(1):105–120. [PubMed: 11949915]
2. Zazove P, Niemann LC, Gorenflo DW, et al. The health status and health care utilization of deaf and hard-of-hearing persons. *Arch Fam Med.* 1993; 2(7):745–752. [PubMed: 8111500]
3. Vernon M, Leigh IW. Mental health services for people who are deaf. *Am Ann Deaf.* 2007; 152(4): 374–381. [PubMed: 18257506]
4. Newfoundland and Labrador Association of the Deaf. Employment and employability in the deaf community: an employability strategy for deaf people within the Northeast Avalon Region. St. John's: author; 2007.
5. Bamett S. Clinical and cultural issues in caring for deaf people. *Fam Med.* 1999; 31(1):17–22. [PubMed: 9987607]
6. Parise, N. Breaking cultural barriers to health care: the voice of the deaf [thesis]. Montreal: McGill University, School of Nursing; 1999.
7. Steinberg AG, Bamett S, Meador HE, et al. Health care system accessibility: experiences and perceptions of deaf people. *J Gen Intern Med.* 2006; 21:260–266. [PubMed: 16499543]
8. Public Health Agency of Canada. What makes Canadians healthy or unhealthy?. Ottawa: author; 2003.
9. Flaskerud J, Winslow B. Conceptualizing vulnerable populations in health related research. *Nurs Res.* 1998; 47(2):69–78. [PubMed: 9536190]
10. Allen B, Meyers N, Sullivan J, et al. American Sign Language and end of life care: research in the deaf community. *HEC Forum.* 2002; 14(3):197–208. [PubMed: 12405039]
11. Kehl KA, Gartner CM. Challenges facing a deaf family member concerning a loved one's dying. *Palliat Med.* 2010; 24(1):88–93. [PubMed: 19910395]
12. McCreary JA, Stebnicki JA, Coeling HV. The culture of the deaf. *J Transcult Nurs.* 1999; 10(4): 350–357. [PubMed: 10693426]
13. Padden, C., Humphries, T. Inside deaf culture. Cambridge: Harvard University Press; 2006.
14. Margellos-Anast H, Hedding T, Perlman T, et al. Developing a standardized comprehensive health survey for use with deaf adults. *Am Ann Deaf.* 2005; 150(4):388–396. [PubMed: 16466194]
15. Statistics Canada. Participation and activity limitation survey 2006: facts on hearing limitations. Ottawa: author; 2006. Fact sheet. Catalogue no. 89–628-X 2009012
16. Canadian Association of the Deaf. Statistics on deaf Canadians. Ottawa: author; May. 2007
17. Statistics Canada. Canada's population estimate: Atlantic Canada. Ottawa: author; 2011.
18. Statistics Canada. Annual demographic estimates: subprovincial areas, 2005 to 2010. Ottawa: author; 2011. Table 1.1-1, Annual population estimates by census metropolitan area, Canada – population by sex at July 1
19. Ebert DA, Heckerling PS. Communicating with deaf patients: knowledge, beliefs, and practice of physicians. *JAMA.* 1995; 273(3):227–229. [PubMed: 7807662]
20. Lezzoni LL, O'Day BL, Killeen M, et al. Communicating about health care: observations from persons who are deaf or hard of hearing. *Ann Intern Med.* 2004; 140(5):356–362. [PubMed: 14996677]
21. McEwan E, Anton-Culver H. The medical communication of deaf patients. *J Fam Pract.* 1988; 26(3):289–291. [PubMed: 3346631]
22. MacKinney TG, Walters D, Bird GL, et al. Improvements in preventive care and communications for deaf patients: results of a novel primary health care program. *J Gen Intern Med.* 1995; 10(3): 133–137. [PubMed: 7769469]
23. Meador HE, Zazove P. Health care interactions with deaf culture. *J Am Board Fam Pract.* 2005; 18(3):218–222. [PubMed: 15879570]
24. Brick, K. Our civil rights movements: a guide for all. In: Goodstein, H., editor. *The Deaf Way II reader: perspectives from the second international conference on deaf culture.* Washington (DC): Gallaudet University Press; 2006.
25. Cohen, LH. *Train go sorry: inside a deaf world.* Boston: Houghton Mifflin; 1994.

26. Humphries KH, van Doorslaer E. Income-related health inequality in Canada. *Social Sci Med.* 2000; 50(5):663–671.
27. Marchand S, Wikler D, Landesman B. Class, health and justice. *Milbank Q.* 1998; 76(3):305–306.
28. Memon M, Abbas F, Khaonolakar M, et al. Health issues in ethnic minorities: awareness and action. *J R Soc Med.* 2002; 96(6):293–295.
29. Ross NA, Wolfson MC, Dunn JR, et al. Relation between income inequality and mortality in Canada and in the United States: cross sectional assessment using census data and vital statistics. *BMJ.* 2000; 320(7239):898–902. [PubMed: 10741994]
30. Ouellette, SE. Reconstructing deafness: a solution-focused approach to mental health. In: Goodstein, H., editor. *The Deaf Way II reader perspectives from the second international conference on deaf culture.* Washington (DC): Gallaudet University Press; 2006.
31. Erlandson, DA., Harris, EL., Skipper, BL., et al. *Doing naturalistic inquiry: a guide to methods.* Thousand Oaks (CA): Sage; 1993.
32. Lincoln, YS., Guba, EG. *Naturalistic inquiry.* Newbury Park (CA): Sage; 1985.
33. Kemmis, S., McTaggart, R. Participatory action research. In: Denzin, NK., Lincoln, YS., editors. *Handbook of qualitative research. 2.* Thousand Oaks (CA): Sage; 2000.
34. Silverman, D. *Doing qualitative research: a practical handbook.* Thousand Oaks (CA): Sage; 2000.
35. Flynn JP. Snowball sampling for voluntary participation. *J Voluntary Action Res.* 1973; 2(1):60–63.
36. Vidich, AJ., Lyman, SM. Qualitative methods: their history in sociology and anthropology. In: Denzin, NK., Lincoln, YS., editors. *Handbook of qualitative research. 2.* Thousand Oaks (CA): Sage; 2000.
37. Coffey, A., Atkinson, P. *Making sense of qualitative data: complementary research strategies.* Thousand Oaks (CA): Sage; 1996.
38. Van Dijk TA. Principles of critical discourse analysis. *Discourse Soc.* 1993; 4(2):249–283.
39. Acker S. In/out/side: positioning the researcher in feminist qualitative research. *Resources Feminist Res.* 2001; 28:153–172.
40. Tomlinson D, von Baeyer CL, Stinson JN, et al. A systematic review of faces scales for the self-report of pain intensity in children. *Pediatrics.* 2010; 126(5):e1168–e1198. [PubMed: 20921070]