Reducing health disparities in the Deaf community
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The impact of interpreters and the rise of deaf healthcare professionals

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1 Introduction

Deaf communities are as diverse as any other patient population – culturally, linguistically, and socially – and there are many important factors to consider related to their healthcare and communication. As with other underserved healthcare minority groups, deaf people are at higher risk for experiencing serious healthcare disparities as compared to the general population. Signed language interpreters with specialised training in healthcare can contribute to reducing those disparities through multiple channels. It should be noted that interpreters are not the only avenue available to deaf patients seeking healthcare and, in many cases, using a language-concordant provider or a healthcare programme that is run by and for deaf people, may be the preferred choice for the patient. However, in this chapter we will explore the systems within which qualified healthcare interpreters work and their impacts on the health of the Deaf and Hard of Hearing (DHH) community.

We begin this chapter by briefly defining concepts fundamental to signed language interpreting and summarising the relevant similarities and differences between signed language and spoken language interpreting in healthcare settings. From there, we describe historical perspectives on and critical issues in healthcare interpreting. We then explore the health disparities affecting the deaf population, followed by the means through which professional interpreting can impact deaf health outcomes. We will also address the significance of interpreters for deaf professionals seeking training and practice as clinicians, leading to critically important language concordance between deaf clinicians and deaf patients.

2 Definitions and comparisons

Signed languages are naturally occurring languages that have been in existence for as long as there have been deaf people in contact with each other. Although many people assume
that signed language is universal, it is not. Another common misconception is that if regions or countries share a common spoken language, they will also share a common signed language. As an example, although English is spoken in the United States, the United Kingdom, Ireland and Australia, each country, or sometimes region, has its own signed language. Some countries, such as Mexico, have more than one signed language. Most signed languages are referred to by acronyms, e.g. Nederlandse Gebarentaal, NGT (Netherlands); Lengua de Signos Española, LSE (one of the signed languages used in Spain); American Sign Language, ASL (used in the United States and parts of Canada); and Polski Język Migowy, PJM (Poland). It is also worth mentioning that the DHH community comprises a widely heterogeneous range of linguistic, communicative and adaptive preferences and skills, and that signed language is only one of the various forms of communication. Other forms include spoken and written language (e.g. English, Japanese), signed communication apart from formal languages (e.g. cued speech, Signed Exact English), speech-reading, and the use of hearing aids, cochlear implants, or other adaptive technologies.

Signed language interpreting is often described as bimodal because interpreters frequently work between a language that is signed – produced by the hands, face, and body and perceived by the eyes – and a language that is spoken, that is produced through vocalisation and perceived auditorily. However, signed language interpreters also work between different signed languages (e.g. between ASL and LSE). In contrast, the work of spoken language interpreters is usually unimodal, working between languages that are conveyed in a spoken mode (e.g. spoken English and spoken Spanish).

In dialogic medical settings, such as doctor-patient interviews, spoken language interpreters will often use a consecutive mode for a variety of reasons, including the avoidance of interference that may occur when two people speak at the same time. Signed language interpreters have traditionally been taught to interpret primarily in the simultaneous mode, despite studies indicating benefits of consecutive interpreting (Russell 2005). A professional signed language interpreter considers several factors when determining whether consecutive interpreting, simultaneous interpreting, or moving between both formats is most effective for communication in a given situation. If a patient is telling an emotional story that they have been reticent to reveal, simultaneous interpreting may be preferable. If a series of questions is being asked or when an interpreting team is being used (trilingual and/or deaf-hearing team), consecutive interpreting may be preferable. Whatever the mode, healthcare providers need to remain cognisant of non-verbal interactional behaviours that establish therapeutic rapport with the patient even in the presence of an interpreter (e.g. producing emotionally appropriate expressions, looking directly at the DHH patient).

Healthcare interpreting may be carried out through several different types of interpreting teams. In areas with high numbers of immigrants and refugees, it is becoming more common for signed language interpreters to work with three languages (trilingual interpreting). This is illustrated by an example from the United States in which the physician speaks only English, the mother of a deaf teenage patient speaks only Spanish, and the patient uses only ASL. In this case, the trilingual interpreter goes between spoken English, spoken Spanish, and ASL. If a trilingual interpreter with fluency in these three languages is not available, the services of two interpreters would be required: a Spanish/English interpreter and an ASL/English interpreter.

Increasing evidence suggests that teams consisting of an interpreter who is deaf and an interpreter who can hear may be an effective option in healthcare. In medical contexts,
there is often a lack of lexical correspondence between a signed language (e.g. ASL) and the spoken language (e.g. English) for specialised terminology, an issue often complicated by regional variations (or dialects) in sign use. Standard signs may exist for concepts such as diabetes and blood pressure but not for glaucoma, osteoporosis or hormones. Signed languages have a rich array of linguistic features for expressing medical concepts and deaf interpreters, as native or near-native users of ASL, may be more effective in using these linguistic features in interpreting than hearing interpreters who learn signed language as an adult. Furthermore, deaf interpreters have cultural competencies that may not be as deeply developed in hearing interpreters; those competencies may positively inform the development of strong therapeutic rapports between the patient and clinician in the context of potentially stressful medical issues. The following are examples when a deaf interpreter or a deaf clinician fluent in sign language may best serve the needs of the patient:

- A deaf patient who is an immigrant or refugee
- A deaf patient with limited health literacy
- Situations that involve deaf children or elderly patients (or others) with idiosyncratic ways of signing, and
- A deaf patient with mental health or cognitive issues

Some clinics and hospitals have common medical forms translated into multiple languages. For deaf patients, these forms are translated into the local signed language and presented in a video format. Translation work from written language to the signed language of the local deaf community (or vice versa), is frequently done by translators who are deaf and often performed by teams. Since signed languages do not have written forms, a translation is usually done from a printed document (the written form of the local spoken language) to a video-recorded translation in the patient’s signed language or from a video recording in a signed language to a written document.

Some signed language interpreters specialise in working with people who are DeafBlind. People who are DeafBlind prefer different types of interpreting and may use a signed language interpreter at close visual range or tactile interpreting which is received by the DeafBlind person by touch with one or two hands. ProTactile is a newer approach that began in 2007 and has since gained momentum. Developed by DeafBlind people, ProTactile supports access to the world through touch, providing signers with rich information about the environment, non-verbal responses of interlocutors, and other critical information. One of the central ideas behind the philosophy of ProTactile is that DeafBlind people can achieve all human activities – learning, communicating, building, navigating – by touch. Vision and hearing are not required. According to two leaders of the ProTactile movement, Jelica Nuccio and aj granda, ‘Protactile philosophy has grown out of the realisation that DeafBlind people’s intuitions about tactile communication are stronger than the intuitions sighted people have. This realisation has changed the way we communicate with each other, the way we work with interpreters, and more generally, the way we live’ (DeafBlind Interpreting National Training and Resource Center).

Increasingly, interpreters are being trained by DeafBlind ProTactile experts in the philosophy and use of ProTactile. Recent research from Edwards (2014) documents some of the differences between visual ASL and ProTactile ASL.

Signed language interpreters who grew up in deaf families, often referred to as heritage signers, are recognised as having cultural and linguistic knowledge that makes them suitable for developing professional interpreting competencies. In many countries, these
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individuals may also be referred to as Codas. Originally this stood for ‘children of deaf adults’ and now refers to a hearing person with one deaf parent. CODA International is a worldwide organisation with a presence in many places including Ireland, Hong Kong, Germany, France and Italy. Although some deaf people may want trusted family members or friends who sign to be part of the medical interview, care should be taken to not confuse a relative, family member or friend who signs with a professionally prepared interpreter. Family members and friends have a different role in healthcare interpreted interactions than a professionally trained interpreter; as *ad hoc* interpreters with roles influenced by emotional and other factors, they may adversely impact the accuracy of the interpreted message.

**2.1 Areas of similarity and difference for signed language interpreters and spoken language interpreters**

There are many similarities between signed language and spoken language interpreters in healthcare settings. Both spoken and signed language interpreters may interpret consecutively or simultaneously, as well as perform sight translations. Both signed language and spoken language interpreting have also undergone a process of professionalisation in the last 40 years, including healthcare interpreting. As part of this professionalisation, interpreters of any language pair are expected to understand and apply ethical principles in their decision-making, and be able to accurately monitor their own work. All interpreters must be aware that a purely lexical or phrasal approach – literally trying to match words/signs – does not allow a patient to have meaningful access to the interaction. In some parts of the world, education and training programmes for signed language interpreters and spoken language interpreters have evolved over the years from very short training courses (40 hours or less) to bachelor’s and master’s degree programmes, and have embraced approaches that focus on discourse and interaction. In order to interpret effectively, interpreters need to know something about the purpose and goals of the medical encounter before interpreting. Furthermore, the healthcare encounter is likely to be most successful when the clinician, patient and interpreter all share an understanding of the interpreter’s role and when the healthcare providers have had training in working with an interpreter. For example, the clinician’s use of visual aids, such as anatomical models or diagrams, is often beneficial for communication for all parties.

In addition to generalist competencies, interpreters working in healthcare settings need expertise related to the healthcare context. As an example, below are qualifications for ASL/English medical interpreters, developed by a national expert panel (Swabey and Craft Farber 2012):

- Bilingual fluency in English and ASL, including the ability to produce and comprehend sociolinguistic variation
- Understanding of linguistic, social and cultural influences that impact healthcare interactions (e.g. specialised vocabulary, discourse styles, language register, dynamics of power and prestige between interlocutors, and triadic communication)
- Adhering to the Registry of Interpreters for the Deaf and the National Association of the Deaf Code of Professional Conduct and familiarity with the National Council on Interpreting in Health Care code of ethics
- Balancing the need for maintaining professional distance with empathy and flexibility
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- Knowing the laws and policies related to healthcare settings (e.g., liability, Americans with Disabilities Act, state-specific human rights laws, hospital policies)
- Knowing the general physiological and psychological implications of healthcare
- Understanding of various healthcare approaches (e.g., Chinese medicine, ayurvedic, holistic, homeopathic, Western medicine, hospice)
- Understanding underlying practices of various healthcare delivery systems and the role of self and others on the healthcare team (e.g., employing CDIs, Deaf Community Healthcare Workers [CHWs] and advocates when they can enhance the communication)
- Sharing information and resources about communication through advocacy, leadership and education in healthcare settings

Preparation, reflection and professional development are important for all interpreters; and where available, interpreters who work in healthcare should pursue advanced training and credentialing in healthcare interpreting.

Although both spoken language interpreters and signed language interpreters provide valuable and needed services in healthcare settings, the phrase ‘the illusion of inclusion’ is used more frequently as the population that uses interpreting becomes increasingly diverse. The assumption that providing a patient with an interpreter automatically means equal access is a notion that needs to be examined. There are many factors in play – for example, the skills and knowledge of the interpreter, including the ability to convey discourse functions, the communication needs and preferences of the interlocuters, the background/contextual knowledge about the topic/situation, and the demands of the particular interaction. Related to signed language interpreting across all settings, De Meulder and Haualand (2019) make the case that the provision of interpreting services should not be synonymous with access.

Regarding the differences between spoken language and signed language interpreting in healthcare settings, interpreting with deaf patients or deaf healthcare providers requires attention to placement of people and equipment that differ from the requirements for interactions between non-deaf patients and providers. Spoken language interpreting can occur via telephone/audio conferencing or with the interpreter behind a privacy screen. However, deaf people and signed language interpreters must be able to see each other in order to communicate, thus neither audio conferencing nor interpreting behind a screen are available options. Video relay and video remote interpreting may be used in healthcare situations with deaf patients. However, in many situations, an onsite interpreter is preferable and a video interpreter is used only until the onsite interpreter arrives. Some of the challenges include technical inadequacies (e.g., the strength of the internet connection in order to have a clear and consistent video of the interpretation), the inability of the patient to see the video screen due to musculoskeletal or other clinical hindrances, and the ability to move the video interpreting technology quickly and efficiently with the patient into different rooms/areas (which can lead to frequently dropped connections).

There are other settings in which consideration needs to be given to how the patient will have visual access to the situation, including the ability to see the interpretation clearly. Examples include:

- When the patient is face down for an examination or treatment
- A room for an eye examination where the lights are turned down or out
- When the doctor is speaking to a patient who cannot keep their eyes open
The interpreter must also be well prepared to interpret for deaf patients who have limited use of their hands and arms due to illness, injury, or IVs. For patients who have back, head or neck injuries, finding a position that allows for effective visual communication can be challenging. Ideally, the patient, the provider and the interpreter should be able to see each other, as this is one component of rapport building which is crucial for the patient-clinician relationship.

Another difference between signed language and spoken language interpreters is that, as mentioned earlier, signed language interpreters are not always trained in consecutive interpreting and notetaking, although these are competencies commonly incorporated into spoken language community interpreting programmes. Spoken language interpreters have a long history in the areas of translation and conference interpreting. In comparison, these are relatively new fields of professional study and training for signed language interpreters. Interpreting services for refugees and immigrants reveal further differences between spoken and signed languages. While it is sometimes assumed or expected that people from these groups will learn the language of the area and not need interpreting services across their lifespan, deaf people use interpreters across all ages and stages of life. The laws for providing interpreting services for non-deaf immigrants and refugees are different in many countries form what they are for deaf people; for the latter, legal requirements often focus on the framework of disability. Finally, for immigrants and refugees who are patients in healthcare systems and use interpreters to communicate with healthcare providers, there is an imbalance of power. Although this is true for many patients who are deaf, as this chapter later points out, deaf physicians and other healthcare providers who are deaf can be the ones using an interpreter in their professional role in a clinic or hospital, reinforcing the aforementioned concept of deaf people often working with interpreters through different times and in varying roles across their lives. As will be described later in this chapter, interpreters working with deaf healthcare providers need specialised training, education and skills.

In order to interpret effectively between deaf patients and hearing clinicians, it is important for interpreters to explore the deaf perspective of the inequities and challenges many deaf people experience when they try to access healthcare services and the impact that the historical oppression of deaf people has had on health. The next section therefore provides foundational information that is crucial for signed language interpreters working in healthcare settings.

2.2 Healthcare disparities in the Deaf community

People in the DHH community experience significant health disparities, as compared to the general population. A health disparity occurs when a particular health outcome (such as the incidence of diabetes, smoking prevalence, or death) occurs significantly more often in a certain subpopulation than another. Healthy People 2020 defines health disparity as ‘a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage’. The means by which health disparities arise are numerous and complex, ranging from nutrition to racism. Among the factors contributing to health disparities is deafness, and poor access to communication has been identified as a major cause of this disparity.

When growing up, people can learn about health issues through formal and incidental pathways. Formal pathways include health education classes, receiving advice from one’s physician, and reading about health information. Incidental learning, on the other hand,
occurs by picking up cues and information in one’s environment. These can include listening to one’s parents while they discuss their own health information (or that of other family members) with their physicians, with friends in person, or over the phone; this learning can even take place when listening to television commercials about medications. The process of naming and describing one’s own health issues can be acquired in similar fashion. The DHH child with one or more DHH parents is more likely to have mutual access to communication and thus incidentally learn, a statement which has been supported in early retrospective work (Hall et al. 2018). When one is DHH with hearing parents, which is estimated to occur among 90 per cent of the DHH population, one frequently cannot overhear such comments, and thus must rely dominantly, if not fully, on formal learning mechanisms about healthcare.

What barriers then exist with formal learning mechanisms? For the written word, health information in the United States is often published above approximately the reading level of the average 11- to 12-year old, while the data suggest that the average DHH American’s reading level is notably lower. If a DHH person were to seek information published in a signed language format, such as a video online or via social media, few well developed or validated resources exist, even though it has been shown that such sign-based resources are effective in improving DHH people’s health knowledge (Zazove 2012).

Although visits to one’s physician are frequently seen as the primary resource of individualised health care and education, this is not always the case for the DHH community. In multiple studies, deaf people have identified inadequate communication as a dominant barrier to fully accessing and optimising their healthcare (O’Day et al. 2004). Many people think first of face-to-face communication; in this situation, DHH patients have reported experiencing providers’ inaccurate assumptions without first engaging the DHH person. For those who rely on spoken language and speech-reading, more time is often needed to understand others’ speech, yet providers and clinical staff may speak too quickly or without looking directly at the DHH person. The limited literacy of some DHH people precludes note-writing as an effective means of discussing complex health-related information, from symptomatology to possible diagnoses to complex health management planning. Some have reported that, if their English proficiency is limited, they perceive that physicians underestimate their intelligence and may not fully engage the DHH person during interviews, physical examinations, or even medical procedures, increasing the risk of patient discomfort, confusion and fear. Such barriers impact DHH people internationally; in a survey of deaf adolescents in Ghana, many reported struggling to access healthcare communication effectively due to the absence of resources available for those who sign (Senayah et al. 2018). Similarly, a focus group study of hospitalised Italian deaf people sustained the theme of communicative disempowerment (Sirch, Salvador and Palese 2017).

What specific health disparities impact the DHH population as a result of these barriers and challenges? Research thus far has identified a number of areas, mostly via surveys. Health knowledge comprises the largest domain for disparities studied in the literature, particularly among DHH people who use primarily signed language. A study in the 1990s of DHH people’s health literacy showed less understanding of risk factors for acquiring HIV (Human Immunodeficiency Virus); these results persisted in studies in the 2000s, suggesting little progress over that decade in the United States (Heuttel 2001; Bat-Chava, Martin and Kosciw 2005). Similar findings have been reported in Swaziland and Brazil (Groce et al. 2006; Bisol et al. 2008). Deaf women in focus groups reflected lower understanding of the value of mammograms and Pap smears in cancer surveillance...
(Steinberg et al. 2002); a survey of DHH women and men published in 2018 showed similarly low understanding of HPV’s relevance to cervical cancer and whether HPV vaccination would reduce the risk of cervical cancer (Spellun, Moreland and Kushalnagar 2018). Orsi et al. found persisting low knowledge of Pap smear value (2007). Fewer than half of a study’s respondents recognised chest discomfort as a potential sign of a heart attack (Margellos-Anast, Estarziau and Kaufman 2006). Overall knowledge about cancer prevention intervention knowledge has been noted to be low as well (Zazove et al. 2009). Such disparities extend beyond the domain of clinical knowledge and impact DHH people’s physical health, the use of healthcare services, and even healthcare outcomes. For instance, marked food insecurity has been reported by DHH people at higher rates than the general US population; such food insecurity correlates with having worse overall health (Kushalnagar et al. (2018). DHH people might use the emergency departments more often than the general population (McKee et al. 2015), and Mitra et al. (2016) identified worse perinatal outcomes for pregnant women with hearing loss.

3 Historical perspectives

Signed languages have existed throughout time in all parts of the world in which there have been deaf people living within a community. Just as long, members of these communities have been called upon to act as (ad hoc, or untrained) interpreters (Stone 2009). Although the documentation to date is sparse, there are records of signed language interpreters being utilised in Europe in the 16th century and in the United States from the beginning of the 19th century. Without training or educational programmes, those who acted as interpreters or translators were often members of a Deaf community, having learned how to sign from deaf family members. In addition, those who worked with deaf individuals as teachers, social workers or clergy often knew some signed language and acted as interpreters. Stone (2009) documented that bilingual deaf members of communities (fluent in the written language of the country as well as the signed language of the country) often functioned as translators. The professionalisation of signed language interpreting – including training programmes, degrees and credentialing – only began in the 1960s and is still in its infancy in many countries. The United States is often recognised as leading the world in the development of signed language research and signed language interpreter training programmes. The civil rights movement that began in the mid-20th century fuelled some of these changes, as well as the recognition of American Sign Language as a naturally occurring language, separate from English. Registry of Interpreters for the Deaf (RID), the national organisation of interpreters in the United States, was established in 1964.

Professional publications and research on signed language interpreting began in the early 1960s, with most of the publications in the 1960s and 1970s coming from the United States and written in English (Metzger 2006; Grbic 2007). In 1978, a conference in Venice brought together spoken and signed language interpreters. At that conference Robert M. Ingram, a pioneer in promoting linguistic research of signed language interpreting, made the argument that ‘no description (practical or theoretical) of interpretation which fails to take account of sign language interpretation can be regarded as complete’ (Ingram 1978: 109). Although this viewpoint was not immediately adopted, the number of signed language interpreting publications increased by the mid- to late 1990s, both in number and country of origin. Initially, signed language and spoken language interpreting developed separately in education, research, publications and conference
programming. Some notable changes to this began in 1995, with the series of Critical Link Conferences which brought together stakeholders from different countries involved in community interpreting in both spoken languages and signed languages, including programme administrators, language planners, educators, researchers and interpreters from across the world. *Introducing Interpreting Studies* (Pöchhacker 2004) was one of the first interpreting studies textbooks to integrate signed language interpreting. Since that time, journals, books, conferences and educational programmes have integrated signed language interpreting as part of interpreting studies, a subfield of the larger academic discipline of translation studies.

In most countries, signed language interpreting was initially a field of ‘generalists’. In other words, those who were fluent in a signed language and spoken language and had well-honed interpreting skills functioned as interpreters in all settings, including medical settings. In the United States, RID began testing and certifying generalist interpreters in 1972. To date, there is not a national certification in healthcare interpreting offered by RID, although some states have certificates or licences for medical interpreting. In the United States, lawsuits filed against hospitals for not providing adequate communication access have also ignited some healthcare systems to institute better policies for providing qualified medical interpreters.

Training and credentialing for signed language interpreters in the United Kingdom and Europe began in the 1970s and in Australia in the 1980s. In contrast to the United States, Australia has a certification system that recognises the specialisation of medical interpreting. However, in many countries, there still are no organised programmes for teaching signed language or signed language interpreting, let alone a specialty such as medical interpreting. Some countries, such as Scotland, New Zealand, Canada and Germany, do have signed language interpreting programmes at the undergraduate or graduate levels. However, many countries in Latin America, Africa and Asia do not have degree programmes in signed language interpreting. Overall, ‘developing’ countries often have no organised training for signed language interpreters. ‘Developed’ countries may have only general training (e.g. workshops, short courses) or full degree programmes at the undergraduate or graduate levels. Few countries have in-depth, specialised training in healthcare interpreting. Even in countries with qualified, trained healthcare interpreters, a request for a qualified healthcare interpreter at a specific time and place often cannot be fulfilled due to the imbalance between supply and demand, particularly in rural areas.

Even with the advancements in the last 40 years to professionalise signed language interpreting, and more recently to provide specialised training in healthcare interpreting, access to interpreting services is still a challenge for many deaf patients. As interpreters gained education and credentials, they also expected to be compensated for their services, just as other professionals are in health settings. However, the responsibility of paying for a signed language interpreter in healthcare settings varies, depending on many factors. In the United States, legislation requires that hospitals and clinics provide access to people with disabilities, including the provision of interpreters for deaf people. However, deaf people still identify healthcare as one of the most difficult settings in which to attain a qualified interpreter. In most European countries, the government is responsible for funding the cost of interpreters in medical settings, although there are restrictions. For example, in the Netherlands, deaf people have a right to an interpreter at no cost for 15 per cent of their work time, 100 per cent of their education, and then only 30 hours a year for other situations (De Wit 2016). Further, even if the government is responsible for the expense of an interpreter, there may not be an interpreter or a reliable service that connects deaf
patients with qualified interpreters available at the time they are needed. In two European countries, Kosovo and Albania, no payment is available for medical interpreters (De Wit 2016). Similarly, although Uganda has more than 200 certified interpreters, interpreting services remain unfunded by the government. In Albania, Cyprus, France, Germany, Luxembourg, and Turkey, deaf people cannot choose or request a preferred interpreter. Even in countries where this is an option, the preferred interpreter may not be available. Thus, even in very personal, intimate or painful encounters, deaf people may have no control over who will interpret. Specifically, men who prefer a male interpreter may not have that option, even in countries where that request can be made. In the United States and Europe, signed language interpreting is a highly female profession with approximately 87 per cent female (self-reported) in the United States (RID, 2018) and 87 per cent in Europe (De Wit 2016).

4 Current contributions and research

Interpreting has been described by Roy and Metzger (2014) as both interdisciplinary and cross-disciplinary. In the former case, this means that interpreting can be studied from a variety of disciplines including, but not limited to: linguistics, psychology, anthropology and sociology. In the latter case, it means that methodologies, frameworks, and theories from more than one discipline can be used to pursue research questions about interpreting. Following this, it is not surprising that qualitative, quantitative and mixed methods are all used in interpreting research. As a snapshot, Liu (2012) analysed the methodologies used in a sample of 48 articles published in the journal Interpreting during the period of 2004–2009, with three special issues on the topic of healthcare. Twenty-six of the 48 studies used a qualitative approach, including grounded theory, action research, and case study. Of the 22 studies that used a quantitative approach as the main method, approaches included descriptive quantitative studies, survey studies, correlational studies and experiments. The methodologies utilised in signed language interpreting research are similar to those used in studies of spoken language interpreting. One major variation exists because of the visual nature of signed language interpreting. To adequately measure, code and analyse signed language, researchers must employ video recording, which can lead to longer timeframes for data processing and analysis. Interpreting in public services settings, including healthcare interpreting, has been a major strand of research in interpreting studies. Signed language interpreting is part of the ‘sociological turn’ that is often described as occurring in interpreting and translation studies over the past 30 years (Angelelli 2012). This ‘turn’ is reflected in the increasing attention in research studies to the agency of interpreters and translators as well as social factors that influence the work of practitioners across all settings, including healthcare.

As recognition for the human rights of deaf citizens to have language and communication access has increased, so has the research that continues to investigate the complexity of bimodal interpreting and communication between deaf and non-deaf patient providers in healthcare settings. Of particular importance is the increase in contributions by interpreters, translators, interpreter educators, and healthcare professionals who are themselves deaf. Similarly, the number of educational programmes that focus on mental and medical healthcare interpreting is slowly increasing, providing much needed education to those who work in these settings. Understanding of the role and decision-making processes of a bimodal interpreter continues to evolve, with important contributions from Metzger (1999) on deconstructing the myth of neutrality, Llewellyn-Jones and Lee
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(2014) redefining the role of the interpreter as having multiple dimensions and fluidity, and Dean and Pollard (2014) on demand control schema and observation and supervision. The need to recognise the importance of interpreters who are deaf and the lived experiences of deaf people has also increased, including the work of Forestal and Cole (2018) who provide a socio-cultural perspective on deaf translation. Interpreting as a social institution, as well as inclusion and access for deaf people, is critically analysed by De Meulder and Haualand (2019). Foundational work regarding the domains and competencies of healthcare interpreters (Swabey and Craft Faber 2012); the identification of task categories and tasks for describing the work of ASL healthcare interpreters, indicating the complexity and multidimensionality of the job (Olson and Swabey 2016), and the development of a career lattice for healthcare interpreters (Swabey et al. 2016) have contributed to the development of education in the United States. The European Union funded the Medisigns project in 2013, which had multiple goals, including the provision of training for interpreters, deaf people and medical professionals to interact more effectively in healthcare encounters. In Australia, Napier and Major have been prolific contributors to healthcare interpreting research (e.g. Major and Napier 2012 and 2019; Major 2014; Major, Napier and Stubbe 2012 and Major et al. 2012). The project Medical Sign Bank: Sign Language Planning and Development in Interpreter-mediated Medical Health Care Delivery for Deaf Australians (Johnston and Napier 2010) is breaking new ground by bringing together stakeholders, including interpreters, linguists, healthcare professionals and members of the deaf community, to create an effective and shared sign language vocabulary for healthcare encounters mediated by interpreters.

De Wit’s (2016) documentation of interpreting services, costs and access helps to build an understanding of the availability of healthcare interpreting services for deaf people in Europe. Studies in Haiti (Hochgesang and McAuliff 2016), Kenya (Mweri, Akaranga and Okomo 2009), and Ghana (Maroney et al. 2018) document the development of signed language interpreting services and interpreting education. Video relay interpreting and video remote interpreting continue to be examined, both for increasing access to healthcare when used appropriately and denying access when used inappropriately (NAD-DSA 2016). It has become increasingly evident that there is a need in most parts of the world for interpreters who are well prepared to work in behavioural health and mental settings.

An example of a programme that prepares experienced generalist interpreters in behavioural and mental health settings consists of a week-long intensive programme followed by observation and case study work, and finally a practicum. If all of these components are completed successfully, there is an eight-hour exam that, if passed, leads to the credential of Qualified Mental Health Interpreter. This programme was developed by the Deaf Services Division of the State of Alabama (Crump 2012) and has resulted in over 125 credentialed mental health interpreters in the United States.

However, it needs to be pointed out that while existing literature reflects significant advances in signed language interpreter education and research, as well as the benefits of clinicians’ working with professional interpreters, many clinicians do not engage interpreters with appropriate training, even to the extent of normalising such behaviour in the context of time and other pressures (Ebert and Heckerling 1995; Diamond 2009). These behaviours have been identified in various places including the United States and Switzerland (Würth et al. 2018). Physicians acknowledge utilising ad hoc interpreters (e.g. family members), recognising the convenience of someone already present and familiar with the patient. Interpreting can also occur via video-based technologies, with the interpreters located off-site; these situations, while often serving when in-person interpreters are not
available, are dependent on intact technology, Internet connections, and appropriate use. Video relay services, for example, may be challenging for the visually impaired or severely ill DHH person. In one national survey, over one-third of DHH respondents reported being dissatisfied with VRI services (Kushalnagar 2019). In one study in South Africa, signed language interpreting use was thought to contribute to more equivalent health care utilisation as compared to the general population (Zulu, Heap and Sinanovic 2017).

4.1 **Language-concordant care and the Deaf community**

While signed language interpreting is a critical means of reducing health disparities, another increasingly important approach exists in the form of language and deafness concordance. Patient-physician concordance occurs when people seeking healthcare share one or more important characteristics with their healthcare providers. Those characteristics can include race, ethnicity, military veteran status, sex, and gender, among others. Patient-physician concordance in various forms has been shown to improve patient satisfaction and health measures, although the quality and results of studies are heterogeneous. For example, evidence suggests that people with language-concordant physicians have better diabetes control (Parker 2017) and are more likely to discuss dietary and exercise modifications (Eamranond 2009). Race concordance has been linked with more positive patient affect and satisfaction (Cooper 2003) and with generally improved health communication and patient engagement (Shen 2018). Gender concordance may have some effect on cardiovascular disease risk factor control (Schmittdiel 2009). While not uniform, these findings suggest that patient-physician concordance has viable effects on patient care.

Discrimination in healthcare has been well described in the forms of racism and sexism and forms directed at other underserved healthcare minorities; in line with these descriptions, audism is a term coined by a deaf scholar, Tom Humphries, in 1975. It refers to the discrimination of deaf people and parallels other terms that are part of discussions on human rights and oppression, such as racism and classism. Bauman (2004) suggested the following three definitions of audism: ‘The notion that one is superior based on one’s ability to hear or behave in the manner of one who hears; a system of advantage based on hearing ability; a metaphysical orientation that links human identity with speech (p. 245).’ The first definition is the initial seed planted by Tom Humphries (1975). The second is adapted from Wellman’s (1993) definition of racism and is mindful of Lane’s (1992) discussion of institutionalised audism. The third definition was presented at the Deaf Studies VI conference by Bahan and Bauman (2000). It is vital that interpreters are aware of audism, as it permeates almost every situation in which deaf people interact with hearing people.

Research on DHH patient concordance with clinicians, whether through deafness (i.e. with DHH clinicians) or signed communication (i.e. with clinicians who sign fluently) has findings similar to race- and language concordance as described above, though this particular form of deafness concordance has been less explored. In one study, DHH patients with providers who signed were more likely to have received preventive health services (McKee et al. 2011), although no reliable estimate exists to quantify how many physicians sign fluently. Beyond deafness alone, rising numbers of physicians with disabilities have been discussed as a means of improving patient care for those with disabilities, yet another form of concordance (Iezzoni 2016). This can occur by direct care concordance as well as via the impact on social awareness and education of colleagues working with those clinicians with disabilities. The University of Rochester Medical Center’s School of
Medicine is situated in Rochester, NY, where a highly concentrated DHH community resides. To foster greater understanding of the DHH experience, all medical students at this university undergo a simulated exercise in which they take on the role of patients navigating a simulated medical centre, one that functions fully in ASL with DHH community members playing staff and provider roles, with positive feedback from hearing participants (Thew 2012).

4.2 Deaf people as part of the healthcare workforce

Over the last two decades, the numbers of DHH people entering medical and other healthcare professional schools and completing training to become practitioners have rapidly risen. While we have yet to get a sense of the United States’ DHH healthcare workforce as a whole (e.g. nurses, dentists), a 2013 study identified 86 people who identified as DHH physicians or medical students (Moreland et al. 2013). Owing to the snowball sampling approach used, this study did not provide a complete picture of DHH clinicians across the country. No parallel data yet exist in the literature to describe the DHH healthcare workforce in other countries.

In the late 1990s, a small group of DHH physicians formed the Society of Hearing Impaired Physicians; this organisation, along with an email listserv named NOISE created by Dr Danielle Rastetter, facilitated colleagues’ connections with one another on thriving as DHH professionals. Shortly thereafter, in 2000, a small group of DHH veterinarians and physicians formally founded the Association of Healthcare Professionals with Hearing Loss (AMPHL), a group that has grown in size since then and now holds biennial conferences for DHH healthcare professionals, students, and allies focusing on skill development, technological adaptations, and innovations with the aim of supporting the organisation’s mission of advocacy, networking and mentorship.

Along with this growing group has come the need for newly specialised accommodations, including signed language and oral interpreters, in the United States. In the previously mentioned survey (Moreland et al. 2013), DHH physicians and medical students reported using a wide range of accommodations, including signed (23 per cent) and oral (14 per cent) interpreters, and computer-assisted real-time captioning (CART, 21 per cent). While some of those accommodations were reportedly used more often in particular situations (e.g. CART for lectures), interpreters’ skills were employed across the board, from lectures and small group work to clinical administration and teaching. Indeed, DHH physicians utilised interpreters throughout their career stages, from school to residency training to independent practice. The same study reported evidence that physicians’ satisfaction with accommodations correlated positively with career satisfaction and with the likelihood they would recommend a career in medicine to other DHH people. In other words, working well with interpreters seems to correlate with DHH physicians continuing to work in their careers and even potentially recruiting other DHH people into healthcare.

Interpreters have adapted to work effectively with DHH healthcare professionals (DHPs). Many interpreters have adopted more traditional approaches, often working intermittently as contractors when needed by the DHP, and rotating among a pool of other interpreters, dependent on scheduling decisions made by an interpreting agency or other organisation. Over time, in healthcare and in other fields, many deaf professionals (DPs, when used to describe professionals in fields not limited to healthcare) and interpreters formed and maintained long-lasting professional relationships, with numerous benefits noted by both as those longitudinal interpreters became their DPs’ primary and preferred
interpreters. This concept has been called the ‘designated interpreter’ (DI), a term first coined and explored by Hauser, Finch and Hauser (2008), with one chapter focusing on one DP/DI team’s healthcare experience (Earhart and Hauser 2008).

In healthcare, the rapid expansion of the DI concept, in parallel with DHPs’ larger presence, has led to changes in interprofessional dynamics, with the DHP often holding a higher-level degree than the interpreter (Swabey et al. 2016). In these situations, the DI becomes deeply familiar with the terminology, clinical situations, healthcare system and workflow within which the DHP functions. Relatively unusual situations may include frequent medical interpreting over the phone, working night or even 24-hour shifts, interpreting during critical care (‘code blue’) medical emergencies, and functioning in the sterile environment of the operating room. They may have to interpret for hearing clinicians who have a combination of rapid speech, strong accents, and complex terminology with rare pauses (Moreland and Agan 2012). In the case of the DHP who is in training, the DHP and DI often find themselves in a wide range of clinical situations, since students are often expected to learn about and work briefly in a multitude of subspecialties where they may practise after training is completed. DIs, like their DHPs, then face the challenge of regularly acclimatising to new team members as the DHP students rotate from one environment to another.

While many interpreters and DHPs have discussed what constitutes the most appropriate parameters for the DHP/DI relationship, one element with increasing emphasis seems to be the relationship of DHP to DI, and how they explicitly or unintentionally determine the boundaries of their professional spaces and relationships. Examples range from more concrete decisions such as where the DHI should stand, to broader concepts such as what channels and modes of feedback the team will use with one another (Agan 2018).

The opportunities for further exploration are rich. The very definition of a DI may have evolved. Some see the DHP-DI relationship as one shaped primarily by the DHP’s values and preferences in their clinical role, while others may perceive it as a mutual partnership (Agan 2018; personal communication, Featherstone 2019, Moreland et al. 2013). Delineating the factors underlying the optimisation of an effective relationship will be critical, possibly drawing from other disciplines relevant to interprofessional communication, including in training environments. Training opportunities as a DI are in their infancy, with some content as part of a larger programme being developed (Hall, Elliott and Cullen 2019), and their experiences only beginning to be described in innovative fashion (Argenyi 2019, Moreland and Agan, 2012).

Finally, the DHH healthcare workforce needs to be more fully explored. Our understanding is currently limited to the workforce subset of physicians, physician trainees and medical students; a deeper understanding of other DHH workforce members (e.g. nurses, physical therapists) would paint a broader picture of potential routes of service to the DHH population as well as means of effectively recruiting and retaining DHH people into healthcare careers.

5 Conclusion

Rich in cultural, linguistic, communicative and clinical diversity, deaf and hard of hearing communities across the world face significant health care disparities, in large part due to systemic barriers to communication access; those disparities result in less understanding of one’s own health as well as poorer health outcomes. Signed language interpreters can play powerful roles in facilitating effective communication between DHH patients. Over
the past decades, signed language interpreting as a professionally generalised field has begun to incorporate specialised training in healthcare concepts, terminology and systems, allowing interpreters to function optimally in healthcare climates. That evolution has seen shifts in how signed language interpreters frame decision-making and other aspects of their work, including the inclusion of deaf people as professional interpreters. Another major emergence has been that of DHH people now practising as healthcare professionals, such as physicians and nurses, who likewise may see interpreting services and thus have spurred interpreters’ further specialisation in working with clinicians. Those clinicians and interpreters provide a potent source of communication- and culture-concordant care for DHH people. Along with the increasing inclusion of DHH people as professionals, the education and practice of signed language interpreters continues to evolve, creating multiple potent pathways to improve healthcare outcomes for DHH people.

Further reading


This chapter provides readers with a perspective from interpreters and interpreter educators who themselves are deaf, an important viewpoint that previously has often been missing from the literature.


This chapter provides an in-depth look at what is meant by the concept of ‘accuracy’ when interpreting in the healthcare setting by two prominent scholars in signed language interpreting and translation.


This chapter is written for healthcare clinicians and focuses on language concordance between deaf patients and ASL-skilled clinicians.


This seminal book dispels the pervasive myth of neutrality in signed language interpreting, and includes examples and analyses related to the healthcare context.


This chapter provides an overview of healthcare interpreting in the United States.

Related topics

Community/Liaison Interpreting in Healthcare Settings, Disability in Translation, Healthcare Interpreting Ethics
References


Health disparities in the Deaf community


Spellun, A., Moreland, C. J. and Kushalnagar, P. (2018) ‘Young Deaf Adults’ Knowledge of Human Papillomavirus (HPV) and Perceived Risk of Vaccine in Preventing Cervical, Anal, Penile, and


