Health Care Needs of Deaf Signers

Health Care Needs of Deaf Signers: The Case for Culturally Competent Health Care Providers

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Abstract

There is a need for culturally competent health care providers (HCPs) to provide care to deaf signers, who are members of a linguistic and cultural minority group. Many deaf signers have lower health literacy levels due to deprivation of incidental learning opportunities and inaccessibility of health-related materials, increasing their risk for poorer health outcomes. Communication barriers arise because HCPs are ill-prepared to serve this population, with deaf signers reporting poor-quality interactions. This has translated to errors in diagnosis, patient nonadherence, and ineffective health information, resulting in mistrust of the health care system and reluctance to seek treatment. Sign language interpreters have often not received in-depth medical training, compounding the dynamic process of medical interpreting. HCPs should thus become more culturally competent, empowering them to provide cultural- and language-concordant services to deaf signers. HCPs who received training in cultural competency showed increased knowledge and confidence in interacting with deaf signers. Similarly, deaf signers reported more positive experiences when interacting with medically certified interpreters, HCPs with sign language skills, and practitioners who made an effort to improve communication. However, cultural competency programs within health care education remain inconsistent. Caring for deaf signers requires complex, integrated competencies that need explicit attention and practice repeatedly in realistic, authentic learning tasks ordered from simple to complex. Attention to the needs of deaf signers can start early in the curriculum, using examples of deaf signers in lectures and case discussions, followed by explicit discussions of Deaf cultural norms and the potential risks of low written and spoken language literacy. Students can subsequently engage in role plays with each other or representatives of the local signing deaf community. This would likely ensure that future HCPs are equipped with the knowledge and skills necessary to provide appropriate care and ensure equitable health care access for deaf signers.

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Approximately 70 million people worldwide are deaf and use a sign language.[1] They consider themselves to be members of a linguistic and cultural minority group, as they identify with other deaf signers based on shared experiences of using sign language, being a part of a signing deaf community, and adopting Deaf cultural norms. The lowercase d deaf refers to the audiological condition of not hearing, while the conventional uppercase D Deaf is used to describe their cultural identity. We will, however, use the term "deaf signers" in this article as we recognize that Deaf people may rely on other communication modalities (e.g., lip reading) despite sign language being their preferred language. Thus, in this context, we will be focusing on situations and scenarios in which deaf people use sign language. Many deaf signers do not identify as disabled in terms of the medical model of deafness, as they do not consider their condition to be an impediment and they do not consider themselves to have a hearing loss but a hearing difference.[2] The World Federation of the Deaf asserts that signing deaf communities need linguistic rights, highlighting a critical need for them to receive and give information using a language of their choice (usually their national sign language) in all contexts, including official interactions. Failure to do so not only violates their linguistic rights but also perpetuates the exclusion of deaf signers in society.[3]

In this article, we will highlight the health care-related challenges faced by deaf signers; then highlight the gaps in and importance of culturally competent health care practices, providers, and education; and finally suggest steps that can be taken to embed cultural competence education within health care education.

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Literacy Levels

Those who are hearing-abled learn and develop their knowledge of words and the world in part from observing and listening to conversations around them.[4] Deaf signers are thus deprived of these incidental learning opportunities as health information delivered via radio and television commercials and even overheard conversations of family members' medical histories is not accessible to them.[5–7] Deaf signers also communicate using a visual language, which is unavailable in written format, thereby posing a challenge when it comes to reading health education materials.[8,9] This is further compounded by the fact that only a limited amount of health resources are available in sign language,[10] and the material that is available is frequently written at a reading level that is higher than the recommended sixth-grade level.[11] These factors have led to lower health literacy levels in deaf signers compared with their hearing counterparts with the same level of formal education.[10] For example, there is lower knowledge

of preventive health strategies for cancer among deaf signers in the United States.[12] Additionally, in face-to-face interviews with 203 deaf signers in the United States to assess their knowledge on cardiovascular risks, 40% and 60% of respondents failed to list any symptoms of a heart attack and stroke, respectively. This places them at a higher risk for health problems[5] and results in lower health statuses and poorer health outcomes compared with the general population.[13]

Due to the barriers to acquiring these secondary learning opportunities, deaf signers also have low literacy levels in spoken and written languages, such as English.[5] Indeed, a phenomenological study involving deaf signers in Australia found that due to their lower proficiency in English as well as the lack of health information available in Auslan (Australian Sign Language), these patients faced significant barriers in accessing health information. It was also noted that in instances where information was provided to them in English, they were unable to understand it clearly.[14] This issue is further compounded by commonly held misconceptions that deaf signers can communicate in the local spoken and written language and that sign language is simply a gestured representation of the local language, which it is not. In fact, sign languages differ significantly from spoken and written languages as they are complex visual–spatial languages of their own and contain their own unique syntax and grammatical structures. Altogether, there are over 300 different types of sign languages across the globe,[1] all of which are informed and influenced by local cultural and geographic situations.[15]

Barriers in Communication With Health Care Providers

Members of signing deaf communities face communication barriers with health care providers (HCPs), which contribute to lower health literacy levels and limit access to adequate health care.[9,11,16] In addition, misdiagnosis, delayed treatment, unnecessary testing, and privacy breaches are not uncommon among deaf signers,[16,17] with reports from Australia showing less than 30% of health conditions in this population being diagnosed and treated properly.[18] In the United States, HCPs were perceived as treating deaf signers in a paternalistic manner with treatment provided without patients' full understanding of their health condition or proper informed consent, resulting in nonadherence and compromising the patient's right to autonomy.[16] In addition, very few deaf signers in the United States reported that they were given information by HCPs on preventive health care practices, highlighting gaps in patient education, which were, again, most likely due to communication barriers.[12,16]

Undesirable past experiences with HCPs and HCPs' lack of understanding about deaf signers' needs have fostered distrust, discouraged deaf signers from seeking future medical care, and led to reports of lower satisfaction with their HCPs.[9,17,19,20] This was illustrated in a study in Italy exploring the perspectives of hospitalized deaf signers that revealed vulnerability, discomfort, lack of consonance between care and needs, and disempowerment.[21] In the United States, HCPs themselves expressed that they felt uncomfortable around deaf signers and believed that deaf signers did not trust them,[20] while in Malaysia, HCPs found interacting with deaf signers too time-consuming.[6] It has thus been stressed that as long as communication barriers are not addressed, health inequalities faced by deaf signers will continue to worsen.[19]

There is a growing number of deaf and hard-of-hearing people who have qualified as HCPs in recent years,[22,23] partly due to advancements in technologies, such as amplified stethoscopes, and various legislative changes.[22] These HCPs, who are more likely to be able to have language-concordant patient–provider communication with deaf signers, are likely to communicate more effectively with deaf signers, positively impacting patients' adherence to treatment and recall of medical instructions.[23] Indeed, deaf signers have responded positively to HCPs with sign language skills.[9] The number of deaf-signing HCPs is, however, still low.

Sign Language Interpreter-Mediated Health Care

Sign language interpreters are trained to work in a wide range of public service settings and are bound by a code of ethical conduct whereby they are expected to remain impartial and their presence is only to mediate the communication between parties.[24] In most countries, there is a distinct lack of systematic in-depth medical training for sign language interpreters. The training that is available tends to be ad hoc and not necessarily embedded in formal training curricula (e.g., in universities). There are established best practices, for example, in the United States for training health care interpreters as medical specialists alongside deaf HCPs,[25] but training standards and practices are inconsistent depending on the country.[26]

HCPs and deaf signers do not typically share the same language, so interpreters have to mediate their communications, which can lead to a range of issues. Because of the lack of consistent medical training for interpreters, achieving accuracy in health care interpreting can be a challenge. Interpreters will often be faced with unfamiliar concepts and may not have a full understanding of health care terminology if they have not had appropriate training.[27] There are also risks because there are not always established equivalent medical terms in sign language. Thus, it is difficult for sign language interpreters to prepare for health care interpreting assignments, as they cannot always predict the direction that a health care consultation will take. The success of interpreter-mediated health care interactions depends significantly on the linguistic choices made by interpreters,[28] and untrained interpreters may inappropriately omit or alter important health information.[29] The success of the consultation also relies on HCPs and patients understanding the role of the interpreter.[30,31] Even when health care interpreting services are available with professionally trained and qualified interpreters, deaf signers in various countries still report barriers to accessing health care information.[28,32,33] In this potentially high-consequence setting, "an incorrect explanation of symptoms to the practitioner or incomplete instructions to the patient can have serious ramifications: the wrong diagnosis or treatment can be life threatening."[34] So it is important that interpreters seek clarification from HCPs while interpreting if they do not understand something to ensure that medical information is accurately conveyed and to support the relationship between the HCP and deaf signer.[35,36]

Thus, despite the importance of training medical interpreters, it is also imperative that HCPs do not solely rely on interpreters to mediate interactions with their deaf-signing patients. HCPs themselves should be prepared to provide the best care for their deaf-signing patients by understanding Deaf culture and considering the provision of direct language-concordant services.[37]

Cultural Competency

Culturally incompetent health care practices

Cultural competency in health care has been identified as an important approach to reducing health disparities. It is defined as "a set of congruent behaviors, knowledge, attitudes, and policies […] that enables effective work in cross-cultural situations."[38] The concept of cultural competence has been critiqued and replaced by terms such as critical consciousness[39] or cultural humility,[40] which stress that there is no end point to being competent and that HCPs need to engage in a lifelong process of critical self-awareness and critical reflection in cooperation with patients, communities, and colleagues to bring into check the power imbalances between them and their patients. Cultural competency remains, however, the most used term within medical education and, hence, will be used throughout this article while recognizing its limitations.[41]

Culturally incompetent health care practices continue to propagate health disparities in signing deaf communities, hindering holistic care in the medical setting.[17] Despite the existence of United Nations' goals and United States federal laws that mandate equal access and communication in all health care settings for deaf signers, they continue to receive unequal health care.[42] In a recent *Lancet* review, Wilson et al highlighted HCPs' poor communication skills and lack of understanding of Deaf cultural norms as contributory factors to the barriers to health care faced by deaf signers.[43] Many HCPs are unaware of Deaf cultural norms, which are dependent on their visual–spatial orientation.[20]

There is also a lack of awareness about deaf signers' linguistic rights and the sociocultural aspects of deafness as reported in countries such as the United States, Malaysia, and Greece.[17,20,44,45] In addition, it is well documented that HCPs are generally unprepared to understand or serve the needs of deaf signers, as they lack the training needed to provide linguistically and culturally competent care for these patients.[5,9,19] This will then hinder them from being able to accommodate the special requirements of deaf signers or provide effective health care to these patients.[16] Thus, it has been suggested that competency-based training for HCPs be made more accessible.[43]

Cultural competency as a tool for HCPs

Cultural competence education has become more widespread as a result of a shift in demographics globally. While the available literature initially focused on strategies to improve the quality of care across racial and ethnic groups,[46,47] cultural competence education has more recently expanded to include other marginalized populations, such as the lesbian, gay, bisexual, and transgender (LGBT) community. Indeed, an educational intervention in a primary care clinic reported a significant increase in LGBT knowledge among nursing staff upon completing their cultural competence module.[48] Such benefits can be extended to deaf signers, who are also at risk for stigmatization and/or have differences in health care needs that put them at higher risk of experiencing inequality in the care received.[49]

There is evidence to suggest that Deaf cultural competency training for HCPs can lead to improved health service accessibility.[11,16] In a study comparing medical students trained in American Sign Language (ASL) and Deaf culture versus students who received no training, the former had significantly higher knowledge of Deaf culture. This led to a better understanding of the challenges deaf signers face with the health care system that extended beyond their physiological differences (i.e., their inability to hear) to other issues, such as their fear of mistreatment by staff, limited health literacy, and lack of awareness of medical terms. The authors postulated that this intervention would translate to HCPs, who would then be able to respond to the issues faced by deaf signers in a more effective manner, thereby reducing the health care disparities faced by these patients.[20] Osteopathic medical students who attended a workshop on ASL and Deaf culture also reported significantly higher knowledge of Deaf culture and confidence levels in interacting with deaf signers.[50]

In a study exploring deaf signers' experiences in the health care system, positive experiences, such as improved interactions and being involved in the decision-making process, were related to the presence of medically certified interpreters, HCPs with sign language skills, and practitioners who made an effort to improve communication.[9] Deaf signers' access to health care can be enhanced through modifying the knowledge, attitudes, and behaviors of HCPs,[45] but instilling cultural competence among HCPs is most effective if done at the early stages of HCP education. Thus, educating health care students and incorporating curricula on cultural competence may help to bridge the gap between HCPs and deaf signers.

Cultural competency in health care education

In 2000, the Liaison Committee on Medical Education, which accredits United States' medical schools, introduced a new standard that emphasized the significance of incorporating cultural competency in the medical curricula.[38] While in the United Kingdom, statements referring specifically to communication skills when serving populations who communicated differently due to a disability were highlighted in the 2018 update of the Outcomes for Graduates report by the General Medical Council.[51] No mention, however, was made in reference to Deaf populations specifically. Although there has been an effort by medical schools to adhere to these standards, cultural competency programs often exclude aspects related to signing deaf communities and Deaf cultural norms. This is illustrated in a recent review of medical school interventions on cultural competency, where only 10 out of 154 interventions addressed populations with disability identities and/or Deaf culture.[52]

Pharmacy education institutions have also been slow in the uptake of cultural competency within their curricula with little mention of Deaf interactions.[13] The American College of Clinical Pharmacy has also noted that attempts to incorporate elements of cultural competency into the curricula have

been inconsistent and limited.[53] These inconsistencies in health care education are attributed to a lack of explicit instructional guidelines for cultural competence curricula and insufficient commitment from institutions.[13,52] In addition, cultural competency programs have commonly adopted the categorical approach, which has meant teaching about the specific values, beliefs, and behaviors of certain cultural groups.[54] However, the drawback to this approach is that it runs the risk of oversimplifying cultures and misrepresenting their issues as 1-dimensional and stereotypical.[52] Hence, cultural competency curricula should progress to adopt the cross-cultural approach, which takes into account the sociocultural aspects that might influence the patient's care.[54]

Implications for education

In this article, we have sought to highlight the importance of preparing HCPs for caring for deaf signers. But how should this be approached? Instructional design models generally start with a needs analysis to uncover what students should learn and then a design phase to systematically plan how students can learn this best. It is important to involve all stakeholders in a needs analysis,[55] which, in this case, would mean involving not only teachers but also students, working HCPs, and representatives of signing deaf communities.

Which competencies do HCPs need to care for deaf signers? In this article, we point out that HCPs need to be aware of the potential lower health literacy of deaf signers and the underlying reasons for this, such as a low literacy in spoken and written languages and lack of access to health care information in sign language. However, HCPs will also need to have adequate skills to detect that patients are Deaf and acquire the skills necessary to communicate with them. Pendergrass et al suggest teaching key phrases to facilitate initiation of a visit and explore the deaf signer's communication preference.[56] The exact competencies that students need to acquire may also vary based on local needs, depending, for example, on the health care system, division of tasks between different HCPs, or the availability of qualified sign language interpreters.

Caring adequately for deaf signers requires complex, integrated competencies that need explicit attention and practice repeatedly in realistic, authentic learning tasks ordered from simple to complex.[57] This aligns with modern learning theories[58] that stress the importance of active learning approaches that stimulate applying knowledge in authentic situations, similar to what students will encounter in their professional life, to make sure that students will be able to transfer what they learn to practice. Attention to caring for deaf signers can be part of larger educational interventions focused on developing cultural competency and skills to communicate with many groups who experience health disparities. We would argue that such interventions should be integrated throughout the whole curriculum and not only in a separate (elective) course because this integration will allow students to learn the required competencies in all relevant contexts and make clear that caring for groups experiencing health disparities is a normal part of care. For example, attention to the needs of signing deaf communities can start early on in health care education. Simply using examples of deaf signers in some lectures or case discussions can alert students to the existence of deaf signers and their specific needs. Subsequently, students will need to acquire knowledge about Deaf cultural norms and the potential risks of low written and spoken language literacy. This could, for example, be done in a discussion session centered around patient stories, as these can provide insight, show relevance, and affect students' perspectives in subtle but important ways.[39]

The next step would be to learn how HCPs can communicate with and address the needs of deaf signers. One way to get more insight into the role of HCPs in this regard is to observe role models interacting with deaf signers in the clinic (or videos thereof).[40] Thew et al propose role plays where students practice with a fellow student playing a deaf signer.[59] A similar exercise could be done with simulated patients (actors) who are part of the local signing deaf community. Pendergrass et al suggest that role reversals, that is, students playing the role of deaf signers, allow HCPs to personally experience barriers to communication, autonomy, and privacy.[56] Video-taping role plays or interactions with real deaf signers in the clinic gives students the opportunity to critically review their own communication with deaf signers.[40] In principle, this can also be part of regular assessment activities, as shown by Greene et al who included a case with a transgender patient in an objective structured clinical examination.[60]

Conclusions

The health care disparities faced by deaf signers are exacerbated by HCPs' lack of knowledge about Deaf culture and the health-related challenges faced by this population, such as lower health literacy levels and prior bad experiences with HCPs. The interpretation process between sign language interpreters, HCPs, and deaf signers is a dynamic one, and one which is compounded by the lack of in-depth medical training received by most interpreters. This makes a clear case for the need for HCPs themselves to be trained in cultural competency, which is currently lacking in health care education. Active learning approaches would seem suitable to ensure that future HCPs understand the challenges faced by deaf signers and are trained on how to best care for this subset of patients. This would likely then ensure that deaf signers have equitable access to health care services and better health literacy levels, which will hopefully translate to lower morbidity levels. Future research should focus on evaluating best practices for treating deaf signers, as well as effective educational methods for training health care students and/or HCPs in cultural competency.

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