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Healthcare access for deaf patients – The legal and ethical perspectives

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Abstract

Deaf patients are too often overlooked in our society despite requiring in-depth attention to their specific communication needs. If they are not able to communicate with healthcare professionals, they may be unable to access and receive appropriate care. Yet, medical providers who fail to address patients' linguistic difficulties breach their ethical and professional duties, and face potential malpractice lawsuits. This article aims to highlight the unequal access of medical care by deaf patients and the impact of language barriers. It also provides an overview of medical providers' ethical and legal duties to assist people with hearing disabilities and discusses the benefits of using professional interpreting services and offers recommendations to address the ethical and legal issues faced by medical professionals.

Keywords

Deaf patients, language barriers, professional interpreters, healthcare, video remote interpreting system

Introduction

Deaf people are too often overlooked by our society despite having specific communication needs that must be addressed. The term 'deaf' is often confused with people having all types of hearing issues. However, 'deaf' has a specific definition and is different from being hard of hearing. A person is considered deaf when he/she has little or no functional hearing and depends on visual rather than auditory communication. The deaf communicate by sign language but a hard of hearing person with mild to moderate hearing loss needs auditory devices to communicate with others. In addition to hearing devices and depending on their degree of hearing loss, they might use sign language and/or other ways of communication such as lip-reading, or writing.

Recent censuses carried out worldwide show that 50,000 people living in the UK are deaf and 8.3 million have hearing difficulties.[1] Comparatively, 800,000 Australians experience deafness ranging from mild to severe; 30,000 of them are completely deaf.[2] The figures are higher in the USA with 6 million deaf and 38 million with hearing problems.[3] Some people are born deaf (e.g. antenatal or postnatal illnesses) while others become deaf and/or hard of hearing during childhood or adulthood (e.g. age, exposure to high level of noise, etc.). Most deaf people believe that they are part of a language community with a real identity and culture. Actually, each country has its own sign language (e.g. American Sign Language, British Sign Language, Australian Sign Language, Italian Sign Language, etc.), and history. Therefore, some do not see their hearing issue as a 'hearing impairment' and might find the term 'impaired' offensive.

Unlike people who cannot speak or read the official language of their country of residence, anti-discrimination legislation implemented worldwide and international conventions protect the deaf community. However, people experiencing deafness still do not have equal access to a variety of services (e.g. education, medicine, workplace, etc.) despite such Acts, the recognition of sign language, and the availability of hearing devices. This article focuses on deaf people's access to healthcare services with an emphasis on the lack of sign language interpreters, key materials, and training. The paper also provides an overview of the medical providers' ethical and legal duties in assisting the

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Deaf community before concluding with some recommendations.

The unequal access to medical services

Like everybody else, the deaf community use different services in society such as education, healthcare, legal, work, and financial services. However, it was reported that deaf people struggle to have equal access to these services on a daily basis, especially in medical settings. Some feel '*trapped*' and '*treated like second-class citizens*',[4] unable to participate properly in their healthcare. Such miscommunication can have serious consequences. Misdiagnosis, mistreatment, and medical errors due to inaccurate or incomplete medical history[5] are among the most serious risks encountered by the deaf community. The same applies to any patient facing language barriers (e.g. illiterates, migrants with low proficiency in the official language of their host country). Studies report that unnecessary lab tests and dissatisfaction with medical services are also among the frequent risks faced by the deaf patients along with an inability to book medical appointments, a lack of follow-up in prescription and medical advice, an increase of emergency visits, and poorer outcomes of care.[6]

Language barriers are mainly due to the attitude, lack of understanding, and poor training of medical staff and healthcare professionals towards deaf patients' needs. Most medical practitioners and their employees assume that deaf patients can lip-read or read written notes[7,8] and do not book an interpreter to assist them. While some who became deaf at a later stage of their life can read notes, others might not be able to lip-read, and those born deaf know only sign language. So the means of communicating with deaf and hard of hearing patients varies greatly. Meanwhile, some medical staff members still do not know how to find and book a sign language interpreter.[9] Consequently, either no interpreter will be provided or there will be a delay and this can cause problems, especially in an emergency.

Cost is another reason that can explain the lack of appropriate communication between deaf patients and healthcare professionals. In some countries, patients bear the cost of a sign language interpreter while in other countries interpreting services are free of charge for patients, but must be funded by hospitals or clinics. For example, in Belgium, patients pay for interpreting services, but the Government of each region (Flanders, Brussels-Capital, Wallonia) refunds deaf people up to 36 h to 45 h of interpreting services per annum.[10] While such a refund policy is a good step forward, the available free hours are sometimes too few for the variety of services the deaf community need to access on a daily basis (e.g. education, bank, healthcare, etc.). By contrast, Norway and Finland refund up to 500 h and 240 h of interpreting services per year, respectively.[10,11]

In countries such as Sweden, Estonia, or Australia, sign language interpreting is provided by the Government for every service and is free of charge for patients.[11,12] In other countries, such as France, the USA, or the UK, medical centres bear the costs of providing sign language interpreters, as it is compulsory to do so under the Hill-Burton Act (USA), the 4th March 2002 Act on patients' rights and the quality of the health system (France), or the Equality Act (UK). Such costs can become a real burden for hospitals which run on a restricted budget. Therefore, medical professionals (and sometimes patients when they run out of interpreting credits) tend to rely on patients' relatives or close friends to interpret.[8,12] They also use other alternatives such as lip-reading and written notes.

There are reports of a shortage of qualified sign language interpreters[12,13] especially in local areas where a face-to-face meeting is needed. One reason is that demand exceeds supply.[13] In the meantime, there are not enough courses or university degrees to help growing awareness and interest in sign language and consequently to train skilled interpreters.[12] This shortage is greater outside urban areas. Technological resources such as videoconference (e.g. Video Remote Interpreting or VRI; Video Relay Service) have been seen as a suitable alternative to assist deaf patients who have responded positively to this idea if they were made available.[10,12]

However, in practice, VRI does not always work properly due to unreliable bandwidth, technical issues (e.g. inaudible sound or frozen screens),[13,14] and lack of mobile or adaptable device to suit the room or the medical centre.[13] Moreover, both medical staff and deaf patients are not sufficiently well trained to use the VRI system properly.[12,15] VRI also requires its users (healthcare professionals, sign language interpreters, deaf patients) to have a computer, an Internet connection, and a webcam as well as the software, which is not always a guarantee.[15] For all the above-mentioned reasons, deaf patients continue to lack equal access to healthcare, and these problems need to be addressed swiftly as they can lead to serious legal and ethical consequences for healthcare practitioners.

The legal and ethical consequences

Unlike people who cannot speak or read the official language of their country of residence and are not protected by any legislation on language services, there are anti-discrimination laws that protect the deaf community. The following table summarises a couple of existing anti-discrimination Acts in some countries

Table 1. Existing anti-discrimination legislation in some countries.

	Legislation
The United Kingdom	Equality Act (2010)
The United States[a]	The American with Disability Act (1990)
Australia[a]	• Disability Discrimination Act (1992) • Disability Discrimination Regulations (1996)
France	• 4th March 2002 Act on patients' rights and the quality of the health system • The hospital patient's Charter Circular DHOS (2nd March 2006) • 11th February 2005 Act on the Equality of rights and Opportunities, Participation and Citizenship of People with Disabilities
Belgium	• General Anti-discrimination Federal Act (2007) • Decree on Equal Opportunity and Equal Treatment (2008) – French speaking Community • Decree on Equal Opportunity and Equal Treatment (2008) – Flemish speaking Community • Decree concerning the fight against certain forms of discrimination (2009) – Walloon region
Canada	• Charter of rights and Freedoms • Canadian Human Rights Act
Germany	Act on Equal opportunities for disabled persons (2002)
Sweden	Health and Medical Service Act (1982)
Finland	Constitution Act (1999)
Norway	National Insurance Act

[a]Federal legislation. Each State has its own Act.

(Table 1). There are also international conventions that protect people with disability such as the Charter of Fundamental Rights of the European Union (2000) or the UN Convention on the Rights of Persons with Disabilities (2006). Such legislation, nationally and internationally, forbids discrimination based on race, age, gender, religion, and disability. Therefore, deaf patients can use these Acts against healthcare professionals who treat them differently due to their hearing disability.

Deaf patients have successfully won their claims based on discrimination and have been awarded compensation up to U$160,000.[16] In the most recent lawsuits reported in the USA and the UK, medical practitioners and hospitals have been found liable for refusing to provide a sign language interpreter on financial grounds[17] or because they believed it was the patient's duty to book and pay for an interpreter.[18,19] In other discrimination cases, some interpreters were provided but were not qualified to carry out medical sign language, or the VRI system used did not work properly leaving deaf patients unable to communicate with medical staff and doctors.[16]

The other major risk for healthcare practitioners is to be held liable for breach of duty in regard to the patients' informed consent. Medical professionals have a duty to provide their patients with the necessary and relevant information about any diagnosis and proposed treatment, investigation, or procedure (common risks and expected benefits) so that patients can assess the pros and cons of any treatment they might undertake before making a decision. It also allows patients to actively participate in their healthcare. To ensure consent is duly informed, the medical practitioner must assess the capacity and understanding of any patient, whether they are under influence of alcohol or substances, are disabled, or are not able to communicate in the official language of their country of residence. Medical practitioners breach their duty of care when they fail to make such an assessment.

For example, in a recent case, a deaf patient made a complaint to the Scotland's Health Service Ombudsman after being left for 12 days without any sign language interpreter and was unable to communicate with medical staff and doctors following her appendicitis surgery. The Ombudsman found that the NHS medical centre failed to comply with their Informed Consent Policy and their legal duty under the Equality Act (section 20). The Ombudsman concluded that the claimant who was unable to lip-read and read written English could not have given informed consent as she was not provided with any sign language interpreter despite pointing to a poster on the wall and presenting an interpreter's card to the medical staff on

two separate occasions. While the hospital contended a lack of sign language interpreters, the Ombudsman found that the medical professionals had not made sufficient efforts to find an interpreter or use an electronic interpreting service.[20,21]

From an ethical point of view, codes of professional conduct in all countries require medical practitioners to respect and be sensitive to any cultural, social, and ethnic differences or disabilities when communicating with patients. Whenever necessary, medical practitioners should use professional interpreters to meet patients' communication needs. Those codes also insist on principles such as professional confidentiality, privacy, and clear and easily accessible communication. In practice, these ethical principles are not fully respected, especially when using ad hoc interpreters, lip-reading, or written notes. Choosing ad hoc interpreters over professional ones represent a confidentiality concern. Unlike qualified interpreters who are independent, impartial, specialised in medical terminology, and are bound to respect patients' confidential information, untrained interpreters are more likely to misuse the information they learn for their own advantage[22] (e.g. information that could be used for insurance policy purposes). Moreover, some patients might not feel comfortable sharing some private details with relatives or close friends.[10,12] Meanwhile, discussion on sensitive topics can inhibit some family members (e.g. a child) from explaining the message accurately.[14,22] This can be a daunting experience with psychological distress.[21,22]

The other issue is that untrained interpreters are not familiar with medical terms. Consequently, they might change the message, add, or omit details delivered by the medical practitioner.[10,22] This may lead to medical errors (some fatal)[21] or misunderstandings that could affect the patient's informed consent and his/her active participation in his/her healthcare. Healthcare professionals can therefore be held responsible for any breach of confidentiality or inappropriate care (e.g. misdiagnosis) related to miscommunication. That is why, whenever possible, it is important to refer to qualified sign language interpreters who have mastered medical terminology and sign language, and respect the code of ethics. There is a need to address the common issues swiftly as more lawsuits are underway[23,24] and one patient has already been reported dead.[25]

Recommendations

Several Deaf Associations worldwide have worked on solutions to improve communication and social integration of deaf patients in medical settings. First, there is a need to increase awareness of deafness among medical staff and medical and paramedical professionals to better assess patients with hearing problems. Such awareness should be provided in addition to existing training courses on medical ethics and legal duties. As discussed above, a patient with mild hearing loss will not communicate in the same way as a deaf patient who only knows sign language. Language barriers are not just physical but encompass the medical staff's attitude towards Deaf patients who are seen '*as a medical* "*problem*"'. Such an attitude leads to stereotypes and exclusion.[11] Showing more empathy and understanding towards deaf patients will improve a patient's satisfaction and follow-up in appointments and taking medication.[9]

Once such an assessment is completed, medical staff and doctors should know how and where to book a sign language interpreter when the need arises (e.g. emergency).[9,10,26] Knowing more about sign language interpreting services also helps with advance booking of qualified interpreters which reduces delay or postponement of medical appointments. Depending on the location of the patients and medical centres – urban or rural areas – a professional sign language interpreter can be booked for a face-to-face appointment, if one is available. Alternatively, the qualified sign language interpreter can be booked by using the VRI system. However, medical centres need to improve the efficiency of their electronic devices (e.g. VRI system; Skype)[26] whether to book appointments or to inform patients of lab results, diagnostic, and treatments. There is no point in having electronic devices that do not work. Medical practitioners will still be liable for misconduct and miscommunication if they fail to provide efficient communication means to patients.

In addition, medical centres should consider a range of technological methods that suit patients with hearing difficulties and, for example, avoid announcing appointments orally but instead send text messages to hard of hearing patients to notify them of medical results or to book medical appointments.[9,26] and consider creating videos in sign language on specific topics to provide deaf patients with key health information.[9,26]

Meanwhile, as part of their anti-discrimination legislation and measures against language barriers to healthcare, local and national authorities need to allocate more funds to hospitals and other medical centres to ensure equal access for all patients.[10] These funds could be used to buy or improve their electronic devices (cf. VRI system) and to create sign language videos, and even to employ casual in-house sign language interpreters.[10]

By the same token, Deaf associations need to keep promoting the need for the training and provision of more qualified professional interpreters as more are urgently needed. The latest figures in the UK indicate

that there are only 800 professional sign language interpreters for 25,000 sign language users[27] out of 50,000 Deaf.[1] Comparatively, there are only around 16,000 qualified sign language interpreters in the USA nationwide[28] and between 350 and 400 accredited sign language interpreters across Australia.[29] Therefore, the issues faced by the Deaf in medical settings need to be addressed collectively to ensure equal access to healthcare and the respect that all patients deserve.

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