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What Clinicians Need to Know About Deaf People

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INTRODUCTION

Deafness is not just an audiogram. It is a physical, psychological and social construct which affects all aspects of a person's life; their identity, their relationships and their functioning in society [1].

One in six of the population has significant deafness, rising to one in three in elderly people. It can have a stigma not associated with sight loss, perhaps because it causes frustration for others as well as the affected person, and this has played a major role in turning a difference into a disability. For people deaf from birth or early life, outdated terms such as "Deaf and Dumb" perpetuate negative attitudes.

Most deaf people had hearing and have acquired, gradually or suddenly, their hearing loss, which may be early or late, partial or severe. In children, especially where medical treatment is not readily available, middle ear infections are a major cause worldwide. In older people, age related changes in the cochlea are the commonest cause [2].

In contrast, one in a thousand people have early profound deafness (Deafness with a capital D). Over ninety percent of Deaf people are born into hearing families. Half the causes are genetic. There are more than eighty genes for Deafness, most of them recessive. The non-genetic causes include maternal rubella, birth hypoxia, neonatal jaundice, measles and meningitis.

If a Deaf child is born into a Deaf family, his or her language acquisition, and emotional and psychological development, will mirror that of a hearing child in a hearing family, in Sign instead of speech. For Deaf children in hearing families, their experience depends on the time and place of their birth. Modern knowledge recognizes that national sign languages are full languages, and are processed in the same part of the brain as spoken languages. The critical age for the development of a first language in early life is also well known. Sadly, until recent years, many policies regarding the education of Deaf children have meant that they were deliberately denied access to sign language in order to force them, often unsuccessfully, to speak. This has had predictable results for the education and psychological and emotional health of generations of Deaf children who were at risk of remaining language deprived or delayed into adult life, with limitations of their literacy and education. Many then learned to sign, and joined their National Deaf Community with its proud cultural heritage, but others remained isolated and marginalized. Communication

Clinicians need to be what is called "Deaf Aware". The basic rule is very simple. D/deaf people hear with their eyes, whether they sign or lip read. If they cannot see you, they don't even know that you are speaking, let alone what you are trying to say. Trying to shout into someone's ear or hearing aid will result in a waltz round the room as they try to lip read you. Two-way communication is the bedrock of clinical practice, and this must be established. Clients/patients will tell you what they need, but you have to ask, and to listen.

For hard of hearing people, with or without hearing aids, there needs to be a quiet place, without the echoing problems of bare floors and walls. There must be good light, but not behind the speaker or shining in the deaf persons eyes. Face the person at a distance comfortable for both of you. No dropping of keys or clicking of pens; these are like gunfire in a hearing aid. No visual distractions like a flashing screen in the background. Speak at a normal pace and volume; shouting distorts lip patterns and makes the speaker look angry and impatient. If a word is missed or misheard, rephrase it. Don't use complex sentences or double negatives. Make topic changes clear. Check comprehension by asking what the deaf person thinks you have said. Sometimes deaf people just nod to please the speaker, even when not completely following what is said, as they are quick to discern any sign of haste or impatience. Writing can be used for clarification, but check that this is acceptable to the client, and don't keep talking while they look down to read. Do not address asides to other people in the room. If you need to examine someone, remember they cannot hear you from behind, or understand you if you are wearing a

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mask.

For Deaf signers, the first priority is an interpreter. Check with the client if they have a preferred interpreter, and provide that person if possible. Sit beside the interpreter, and talk directly to the client who can look at both of you. Everything must be interpreted, so don't say anything that the client should not know. The interpreter remains neutral, and can only intervene in the conversation if he or she thinks that clarification is needed, for example, of a technical term unfamiliar to the interpreter or client. If effective two-way communication is not taking place, for any reason, the interpreter needs to comment on this. Some Deaf people, who have come late to sign language, may not be fluent, and the interpreter needs to recognize this, alert the clinician, and enable clearer communication.

PHYSICAL HEALTH OF DEAF PEOPLE

Deaf people have the same range of physical health needs as the general population, plus the extra risks associated with some causes of deafness. For example, maternal rubella, a cause of partial or profound deafness, can also cause heart problems. Pendred's syndrome, a genetic cause of early profound deafness, also results in thyroid deficiency, which has serious consequences if not diagnosed and effectively treated. Meningitis and some genetic syndromes can have neurological consequences in addition to the deafness. However, deaf people face barriers to physical health care, from making an appointment if they cannot use the telephone, being called into the consulting room if there are just spoken announcements, to communicating with the doctor when they are seen. Sometimes deaf people go with a relative to help them, and the resulting consultation can be like being a pet taken to the veterinary surgery, with everyone having a consultation around them. For Deaf signers seen without an interpreter, because of the trouble or expense, the situation is even worse. Even if relatives can sign, using them as interpreters' breaches confidentiality, distorts information, and can lead to dangerous omissions and misunderstandings. These difficulties can result in delayed and missed diagnoses, and poorer maintenance care for chronic conditions such as diabetes in D/deaf people. Older people are less likely to seek help because of these barriers, and more likely to miss reviews of their health and medication. Public health information can be missed, for example when COVID virus briefings had no sign language interpretation.

MENTAL HEALTH OF DEAF PEOPLE

People who lose their hearing, partially or completely, experience a difficult journey as they risk losing contact with their family and friends, and often their acquired deafness can cost them their job and social role. Confidence and concentration are vital to functioning as a deafened person, but depression can seriously erode these, and may remain untreated as it is attributed to the deafness itself. Technology has a lot to offer, from hearing aids and implants, to alerting devices, subtitling and visual telecommunication, but personal adjustment is also needed, such learning lip reading, and assertiveness in asking for appropriate communication needs. In older people, dementia, deafness and depression are a triad which can reinforce each other, and be missed or misdiagnosed [3].

For Deaf signers, the situation is even more problematic. For this group, there are very limited appropriate and accessible mental health services, even though the prevalence of the whole range of mental health problems is higher than in the general population. There are three main reasons for this. First, there is an excess of "neurological risk" from causes of deafness such as meningitis, birth hypoxia, prematurity and some genetic syndromes. Second, there are all the emotional and psychological pitfalls of a language delayed childhood. In addition, there are risk factors associated with Deaf people's experiences of skewed family relationships, institutional care, abuse and social exclusion. The third factor is the prolonged duration of mental health problems in the Deaf population. Even serious disorders including schizophrenia may be undiagnosed for many years as no one can communicate with the ill person, who may have also have limited and/or distorted sign language. All too often symptoms are just attributed to the deafness.

It is, therefore, vital to obtain full background information, including the cause of deafness and the education history, and to use, if necessary, a Deaf relay interpreter who can adapt to the persons level of sign language. Symptoms such as auditory hallucinations (which Deaf people with schizophrenia can experience) have to be very carefully examined, and can be overlooked or dismissed. Delusional thinking can also be missed or misdiagnosed if the Deaf person has unrealistic ideas due to a limited education.

DEAF BLIND PEOPLE

Blind people rely on their hearing, and deaf people on their sight. Therefore, the effect of both hearing and sight loss is not an addition but a multiplication of the challenges they face. Progressive hearing and sight loss is most common in old age, and is rarely total. However, there are significant numbers of people, more than 20,000 in the UK, who are completely deafblind. Early deafblindnesss is often associated with Intellectual Disability, due to causes like maternal rubella, birth hypoxia, prematurity or meningitis. In adult life, a significant cause is Usher syndrome, a recessive genetic condition with early profound deafness, then progressive tunnel vision due to retinitis pigmentosa. The rarer Usher type 2 causes progressive hearing and sight loss. Type 2 Neurofibromatosis can cause hearing and/or vision loss due to benign tumors on the auditory and visual nerves.

Communication with deafblind people therefore varies according to their individual circumstances, which can change. Cochlear implants or auditory nerve implants may

help. Hands on sign language and fingerspelling or Braille are useful for different people. The person's choice must be respected and provided. Time and patience are necessary, with breaks as required. Never assume that because communication is difficult, that the person has nothing to communicate.

CONCLUSION

Deaf people are varied, just like the general population. Their ways of living in a society in which they are different from the majority depend on individual circumstances and preferences, and most lead full lives. However, many deaf people, particularly those Deaf people who have been affected by past social and educational policies, have had experiences, which can affect their physical or mental health. Enlightened attitudes and appropriate knowledge enable d/Deaf people to lives as equals in society.

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