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## Availability and accessibility of healthcare for deaf and hard of hearing patients

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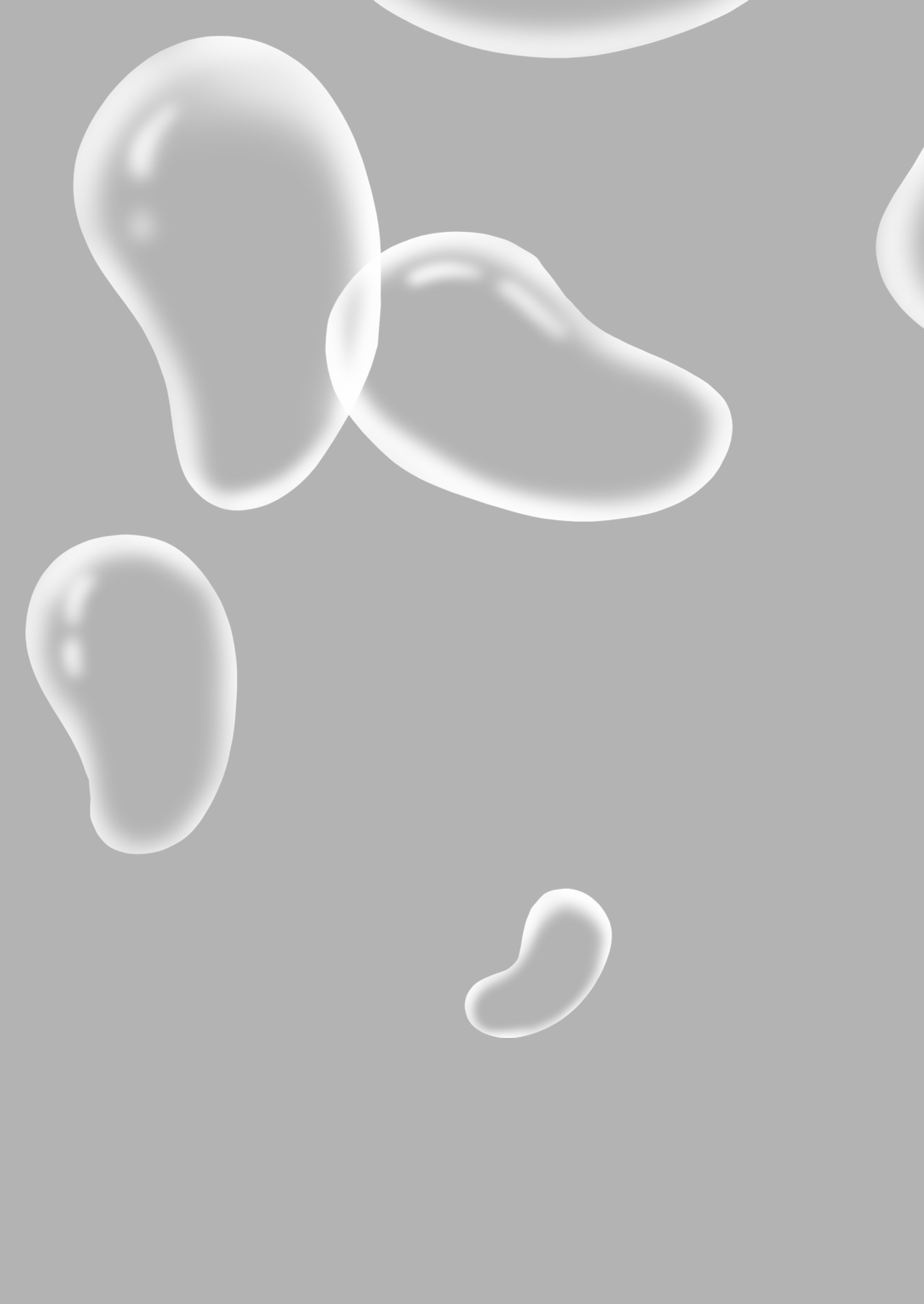


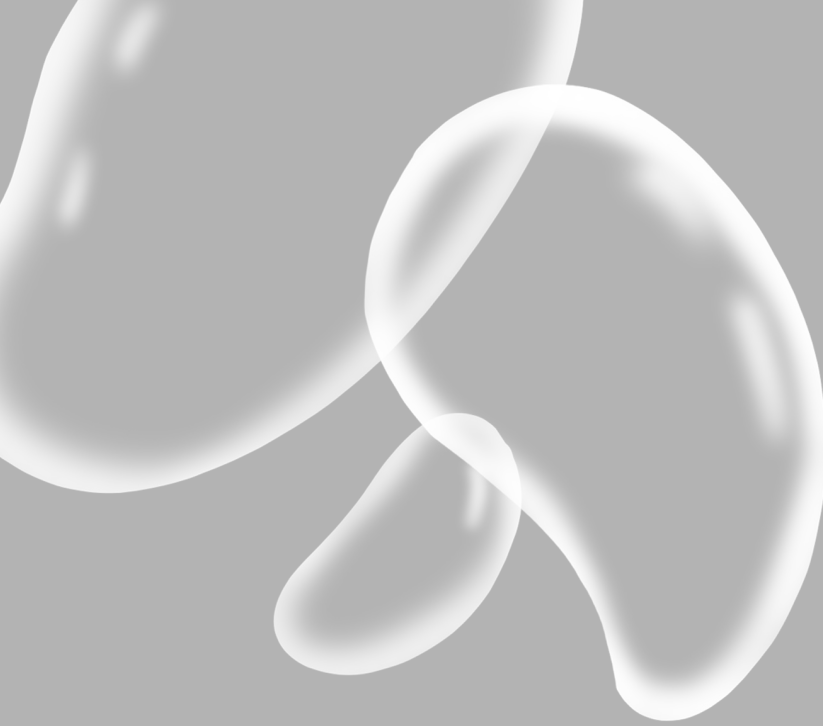
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# 2

## The approach to the deaf or hard of hearing pediatric patient

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## Abstract

Approximately 1 child in 1000 is deaf or severely hard of hearing from birth, and the prevalence rises to about 1.6 per 1000 in adolescents. Providing medical care for this group of children poses special challenges for professionals. To allow a medical consultation to proceed successfully and to the satisfaction of the patient, it is essential that physicians are aware of the different linguistic and cultural background of these patients. Healthcare workers should be aware of the possible higher incidence of co-morbidities, sexual abuse and (psycho)social problems, of the possible pitfalls in obtaining informed consent and higher frequency of medical mistakes. This review describes the communication challenges and medical, ethical and legal issues a physician can experience when faced with these patients.

## Introduction and background information:

Approximately 1 child in 1000 is deaf or severely hard of hearing from birth and the number rises to about 1.6 per 1000 in adolescents. The causes are hereditary in 30%- 39%, acquired in 19%- 30%, and the cause remains unknown in 31%- 48% of the children<sup>[7,8]</sup>.

This article will not focus on different levels of hearing loss. The level of hearing impairment (HI) in decibels (dB) in children does not always have a linear correlation with their actual audiological functioning. Some children with up to 80dB measured HI can function very well with spoken language, while others with 30- to 40-dB HI can face serious communication barriers. Knowing the amount of dB loss will therefore not always be helpful in establishing whether an individual child is mildly, moderately or severely hearing impaired. This is also true for the use of traditional or advanced hearing aids (like cochlear implants), their use is not predictive for the level of functioning.

It is important to realize that when the cochlear implant (CI) is turned off the child is deaf once more. Especially in young children this may be the case during a significant part of the day. The CI has to be taken off for example when sleeping, taking a shower, during swimming lessons or contact sports. Therefore, when we speak of levels of HI, this is defined by the ability of the child to use or understand spoken language.

The volume and quality of research in deaf healthcare facilities has not kept up with research on hearing people. There are probably two main reasons for this. First, a lot of research resources are used to explore the possibilities of improving (spoken) language skills and audiological status. Most of these studies are (in)directly funded by the hearing aid industry, which is not directly interested in observational studies not involving their hearing aid equipment. Second, there are few researchers qualified to do this work, in particular, when requiring sign language fluency and acceptance within the deaf community/ deaf culture<sup>[13]</sup>. Although some experts expect that the challenges in providing healthcare for HI patients involves more than communication, cultural and psychological challenges, we decided to exclude topics on which no scientific evidence is available.

### **What is special about this group?**

HI children are faced with communicative, medical and psychological challenges. It is important for the paediatrician to be aware of these issues and to be familiar with some of the required communication strategies. However, the amount of information available on the special needs of this group is limited and not well known by hearing professionals. In this paper, we will give advice on how to communicate with HI children based on current available information and expert opinion.

### **Deaf culture**

The Deaf community constitutes a social and linguistic minority within the majority 'hearing' culture<sup>[9,11,12]</sup>. A consequence is that problems may arise in communication with the majority hearing population due to cultural and linguistic barriers. These communication problems are comparable to those described in the interaction between healthcare workers and patients from an ethnic minority group<sup>[14]</sup>. For example, deaf patients may be less assertive or show inappropriate assertiveness when visiting a doctor.

### **Developmental issues particular to HI children and adolescents.**

#### ***Language development and sign language***

Generally, people born deaf or with severely HI before the age of 5 years (prelingual phase) face environmental barriers that interfere with their ability to learn a language. Sign languages have complex grammatical structures which allow access to information in a natural way and expression of opinions, desires and abstract thoughts<sup>[1]</sup>.

Most HI children have hearing parents, who are not accustomed to sign language. The quality of the sign input to these children is therefore highly variable, and there is often less or insufficient interaction. Deaf children's access to spoken language is also limited and the relative language deprivation can cause the vocabulary of (young) HI children to be slightly delayed, but apart from this, their language development should be comparable to their hearing peers<sup>[5,10]</sup>. This means that if a HI child shows signs of a language delay or impairment, one should try to find the cause of this delay, considering also other possible causes than just a lack of language input. If no other causes can be found, the language input to the child should be improved.

People who are deaf from an early age often develop low literacy skills. One of the reasons is the alphabetical writing system (letters). When sounds of a language (phonemes) cannot be heard, it is necessary to memorize for a given concept which combinations of letters are used and in which order. Another reason is that deaf people cannot use vocalization when reading. This means that they are only able to read fluently those words that they have read before and of which they have memorized the character construction. In medical consultation, a lot of infrequent and unfamiliar words are usually used. This is why writing down medical information for HI parents or patients may be ineffective. If the main language used in the home is a sign language, then a sign language interpreter should be present during the consultation.

When somebody becomes HI at a later age and has been able to develop normal literacy skills, it can be useful to ask a speech-to-text interpreter to assist the consultation. This is because writing down information by the physician him/herself is time-consuming, resulting in less information being given and longer consultation time.

### ***Lack of knowledge about the human body and health and medical issues***

Education of HI children focuses primarily on their language development, to the disadvantage of general knowledge. Due to the HI, incidental learning is reduced, which leads amongst other things to having less knowledge about their own body, health and feelings. They have little information about what can happen during a visit to the doctor or during hospitalisation or what is relevant for the doctor to know.

Doctors are used to giving information to suit the presumed (cognitive) capacities of patients and their parents. For instance, lack of general and medical knowledge in adolescents is associated with limited cognitive abilities; therefore, a limited amount of simplified information is given. This also often happens when treating intelligent and educated deaf children or parents. These patients regularly report getting either incomprehensible information (start level of information is too high) or only limited information from their doctor (start level of information is good, but does not go deeply enough into the problem later).

### ***Psychological aspects***

Deaf people experience significantly more medical and psychological problems than hearing people<sup>[2]</sup> and often report a lower quality of life on social domains<sup>[3,15]</sup>. Deaf children, even with a minor HI, often miss information during play, and are a target for bullying. Another issue is that the prevalence of sexual abuse is two to three times higher among HI people than among their hearing peers. This is possibly a result of communication barriers and lower social skills<sup>[6]</sup>. When examining HI patients, it is important to be aware of the possibility of psychological and or emotional problems and the high prevalence of sexual abuse.

### **What diagnostic issues are special for these children and adolescents?**

#### Co-morbidity.

Depending on the aetiology of the HI, these children have a higher chance of co-morbidity. Especially when the cause is syndromatic or acquired, the hearing loss may not be the only disability present. Patient delay in seeking medical help due to communication and cultural barriers or due to the lack of health or medical knowledge may lead to extra morbidity.



### History taking

Paediatricians usually obtain some information directly from the child as soon as he or she is able to communicate. When direct communication is complex, it is important to be aware of the possible loss of information. It can be useful to ask for the presence of a mediator such as a sign or speech-to-text interpreter or a healthcare worker who is trained in communication with patients who are HI.

The parents of older HI adolescents and even young adults are often present at consultations because of the communication barriers. Parents often translate signs for their child. Although it is much easier to communicate while parents are present, it is also important to maintain the normal rules of privacy.

Studies show that untrained (family) interpreters leave out or misinterpret up to half the questions asked by the physician<sup>[4]</sup>. Consequently, there is a higher risk of medical mistakes with potentially serious clinical consequences. Importantly, sensitive or embarrassing problems are more likely to be avoided. These studies have been done within spoken populations where the family interpreters are native speakers of both languages. As the signing skills of hearing parents are often limited, it is probable that parents translating for their child, deliver even less quality than mentioned in the studies above. Although parents and the child or adolescent may not agree, it is the decision of the physician or healthcare worker to decide at what age and in which situations it is acceptable for parents to translate and when to bring in a professional interpreter.

### Physical examination and invasive diagnostic procedures

Even very young children receive information when a medical intervention is about to take place. For example, they are told by parents that 'they will get a vaccination'. They might not know what a vaccination is, but they have already developed enough language skills to understand that 'you will get' means that something is going to happen to them. This event can be either pleasant or unpleasant, but the child is, in a way, prepared. In HI children communication is often minimalised. This can lead to insecurity and when these events structurally occur, it can also cause HI children to be less assertive than their hearing peers or lead to a misdirected assertiveness. They are taught that it is normal that things just happen without prior notice and without being able to influence events. Therefore, it is important for the physician to always introduce actions, even when the child is still young.

When a professional (sign) interpreter is present, the doctor must discuss with the patient whether or not the interpreter will be present during physical examination. If not, a thorough explanation is mandatory prior to the planned examination.

After operations, it is often deemed unnecessary to provide the child with hearing aids immediately on waking. Usually this is because the children sleep without a hearing aid at home. However there is a great difference between waking up at home and waking up in hospital after surgery. It is a stressful and uncommon situation and therefore the child needs the hearing aids directly after the procedure.

In most European countries, speech-to-text and sign interpreters are trained in assisting communication during medical procedures. This way the doctor can concentrate fully on the procedure while the interpreter supports the communication.

It is important to be fully aware that magnetic resonance imaging (MRI) is not permitted when a CI is in place. If it should be absolutely necessary, the magnet has to be removed surgically before a MRI scan may be performed.

### **What treatment issues are particular to these children and adolescents?**

In most European countries, the rules state that adolescents between 12 and 14 (or 16) years of age have to give informed consent, together with their parents, before an invasive procedure or proposed treatment is undertaken. Adolescents between 16 and 18 years old are often allowed and expected to make these decisions themselves. As long as the child is still (partially) dependent on the parents for communication, it is difficult to be sure whether full informed consent is given by the child or only by the parents. Therefore it is always necessary to communicate with the child (alone) and check whether he or she really understands all the information. When necessary, an interpreter should assist.

### **Practical conclusion:**

To ensure a successful consultation, it is essential that physicians are aware of the different linguistic and cultural background of their HI patients so that they can take this into account. It can also be useful to have some knowledge about possible co-morbidity (e.g. syndromes). Due to the communication barriers, it is easy to forget to give young children the necessary information. Even though HI adolescents may have different communication needs than their hearing peers, they have the same privacy needs. It is up to the physician or healthcare worker to decide at what age and in which situations it is acceptable for parents to translate and when to bring in a professional interpreter. Also, in order to obtain informed consent, it may be necessary to have a sign or speech-to-text interpreter present.

**General recommendations:**

1. Discuss with your HI patient which method of communication will be used and how communication can be improved.
2. Be aware of possible communication and cultural barriers.
3. Make sure that the practice or hospital can be reached by deaf and hard of hearing patients in emergency situations (also at night and on weekends/holidays).
4. Make sure you have informed consent of both the child and the parents, as necessary.
5. After operations provide the child with hearing aids immediately on waking.

**Recommendations for outpatient services:**

1. Indicate clearly on the file that the patient is deaf so that the practice assistant or nurse (and possible substitutes) is immediately aware of this.
2. Offer the possibility to make appointments and to ask for repeat prescriptions by e-mail.
3. Double consultation time for deaf and hard of hearing patients to be sure there is enough time to make the reason for the visit clear and for providing information.

**Communicational recommendations:**

1. Children and adults who use hearing aids or cochlear implants have problems extracting sounds from the surrounding, so make sure the consultation room is quiet.
2. Sit opposite the HI patient to enable your patient to follow your mouthing whilst you speak.
3. Discuss with the patient whether or not the interpreter will be present during physical examination. If not, thoroughly explain in advance the examination that you plan to do.

**Conflict of interest:**

This paper was not sponsored. All authors report no conflict of interests

**Practical (local) information:**

Italy: [www.robertowirthfund.net](http://www.robertowirthfund.net)

Netherlands: [www.gezondecommunicatie.info](http://www.gezondecommunicatie.info)

United Kingdom: [www.signhealth.org.uk](http://www.signhealth.org.uk)

To our knowledge, the other European countries do not have a central information point for healthcare workers who are faced with HI clients.

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