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

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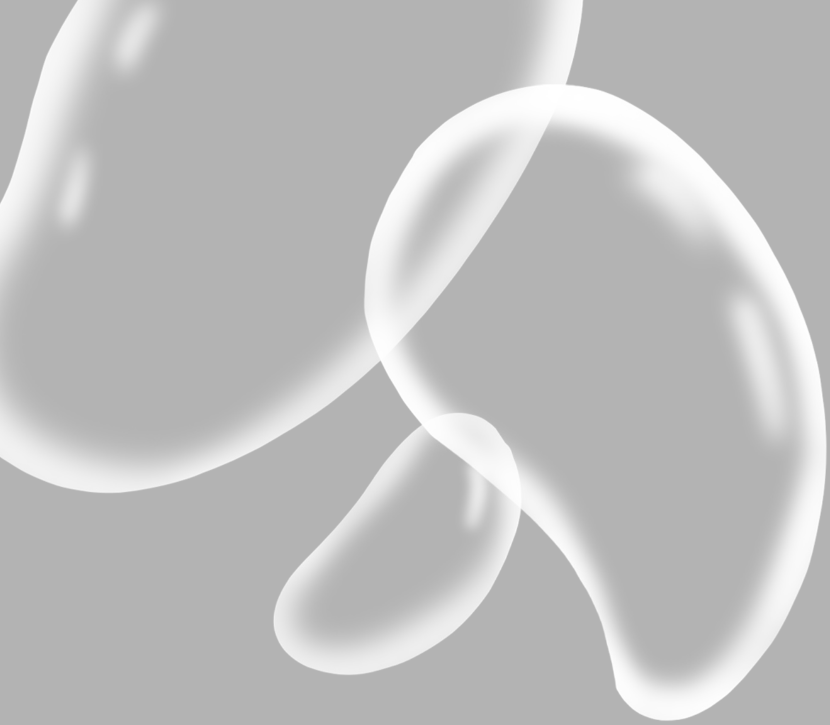

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# General discussion and conclusions

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*Autumn 2007, I am on a train heading home after a three day scientific conference. I went alone, and was not acquainted with the field. This gave me time to observe the scientific merits of the presentations. Sitting at the back of the rooms, I saw a variety of topics passing by. I was impressed by the detailed research questions; so much already known, so many more questions unsolved. Researchers presented studies that did or did not help to find a detail of a puzzle that might benefit future patients. It got me thinking about my current new work field as a physician in a mental healthcare facility for deaf and hard of hearing patients. The extent of neglected physical health problems I saw there had struck me. Some patients do not have mental health problems at all, they exaggerate psychiatric complaints to get to a doctor who can use sign language and finally have their physical problems looked at (and explained to them properly).*

*So much is already known and much has been studied in healthcare research, but my current patient group is overlooked. During my train ride home, I made a list of research questions concerning healthcare provision for people who are Deaf and hard of hearing. This thesis is the first step in providing some answers to these questions.*

**Research area**

The volume and quality of research on healthcare facilities for deaf and hard of hearing people (DHH) has not kept up with research on hearing people. Scientific research focusing on DHH patients using a social model ('how to best deal with the existing functional restriction') instead of a medical model ('how to cure the ear') is a relatively new research direction in the medical field. There are probably two main reasons for this. First, most research is (in)directly funded by the hearing aid industry. These research resources are used to explore the possibilities of improving (spoken) language skills and audiologic status. Second, there are few researchers qualified to do this work, in particular when sign language fluency and acceptance within the Deaf community/ Deaf culture are required.[1]

The complexity and diversity of the group being studied makes it difficult and expensive to carry out qualitatively good research. Adapting standardized tests to use with diverse DHH groups is difficult, expensive and time consuming. Therefore, research methodologies for non-DHH people are often used for DHH participants. The value of the outcomes of these studies is debatable. Study methodologies have to fit the study group, otherwise the outcomes are unreliable.

## Research questions

In this research project we focused on three main questions.

### *Research question 1*

The first research question was 'Do deaf and hard of hearing people (DHH) experience more barriers when they try to access healthcare facilities than people who are not DHH?'

A search of the literature, structured interviews and questionnaires (Section 4) confirm the existence of significant barriers for DHH people in accessing healthcare. The results of our study among Deaf patients and their GPs (Section 4.1) indicate that these barriers hinder healthcare access of DHH people in the same manner as that of patients from other (ethnic) minority groups. We found that in 39% of cases, the communication between the patient and GP was evaluated as either moderate or bad. This result is comparable to what has been found in research on communication between GPs and patients from an ethnic minority group. Van Wieringen et al.[2] found that 33% of patients from an ethnic minority group evaluated the communication with their GP as moderate or bad, whereas a similar negative evaluation is only given by 13% of patients who have the same ethnic background as their GP.

### *Research question 2*

The second question was 'What is the nature of these possible barriers and how large is their impact?'

The barriers in providing healthcare for severely DHH patients can be classed into three groups; a) Communication barriers, b) Barriers due to limited health knowledge and c) Deaf cultural barriers which influence healthcare provision to DHH.

a) Many reports have been written on *communication barriers* when treating a DHH patient. These reports mainly focus on the patient not being able to hear and/ or speak the spoken language of a country.[3] They describe the communication problems and loss of information that occurs when lipreading or writing down information is used as the primary mode of communication between healthcare workers and DHH patients. They emphasize the importance of the use of sign language (SL) interpreters and speech-to-text interpreters. Some reports describe practical problems in accessing healthcare, such as a service that is exclusively accessible by phone. However, these are not the only communication barriers faced by DHH people as patients. Structured interviews and literature searches reveal that linguistic differences between spoken and signed languages, like semantic, phonological and pragmatic differences, are an important barrier as well. These differences lead to loss of nuances in conversation and misunderstanding easily occurs.

b) The second of these barriers *is limited health knowledge.* Deaf education mainly focuses on the acquisition of spoken and written language, often at the cost of general knowledge. Limited exposure to information concerning the body and health in schools for deaf children, contributes to the restricted basic knowledge on these subjects often encountered in many deaf adults.[4] Furthermore, DHH people have no, or very limited, access to 'ambient information', they do not overhear conversations nor hear radio or television announcements. Most hearing people learn about their family's medical history and their own early childhood illnesses by overhearing family conversations or their parents answering questions posed by their physician (incidental learning). Thus, many DHH adults have limited access to information that the average hearing adult would consider common knowledge. Physicians tend to adapt the amount and level of their information to the presumed background and educational level of their patient. Due to lack of knowledge on health matters, DHH people may ask physicians simpler and more basic questions than hearing people with a similar educational level. This may result in physicians underestimating the educational level of their DHH patient. Since the physician may adapt information to this misinterpreted level of education, the likelihood is increased that the patient receives inadequate information.[5] The patient may then complain about being treated in an infantile manner and not receiving complete information, which in turn may increase mistrust in physicians and reduce therapy compliance.[5, 6]

c) The last of the three main barriers is the *influence of Deaf cultural or Deafhood features on healthcare availability*. In our study, we identified six cultural differences between DHH people and non-DHH people that obviously influence healthcare provision. These six are information processing, manners, lack of trust in the hearing world, small community/ need for confidentiality, respect for intelligence and dissemination of information. We will describe these here briefly:

*1) Information processing:* Deaf community members are more likely to get information from each other and have less access to formal information sources.[7] This may lead to problems when the community does not receive complete information or the information is only partially understood.

*2) Manners:* Clearing one's throat or politely saying "excuse me" will not attract a deaf person's attention. In the Deaf community, the usual ways to attract attention include touching someone who is close by, stamping one's feet on the ground, banging a fist on a table (vibrations), or waving a hand within a person's visual field. For the uninitiated hearing person, waving, stamping and banging can seem socially inappropriate.[4] A regularly reported difference in manners recounted in our structured interviews is the process of greeting. Within the Deaf community embracing each other is a very common way of greeting, even when people hardly know each other; this is not always common among non-Deaf people. The way conversations are ended is another example of differences in social norms that may lead to cross-cultural miscommunication. Leave-taking in the Deaf community is usually a prolonged process by hearing-community standards.[8]

*3) Lack of trust:* Severely DHH children lack access to (ambient) information in hearing surroundings such as a healthcare facility. The experience that things happen to them without being informed about what is going to happen and why, makes them more sensitive to feelings of exclusion as adults. Within the Deaf community emphasis is placed on direct information access. The efforts of a hearing physician to gently deliver bad news may be perceived as offensive by a Deaf person who may feel the physician is withholding information.[4] On the other hand, many DHH people also continue to accept this lack of information as a fact of life; In both our structured interviews and in the literature, it was stated that DHH people are less assertive in contact with their physician. That these experiences influence healthcare provision is illustrated by data from Australia and North America, which show similar participation rates to that of hearing people in preventive screening programs, while most deaf participants do not understand what the exact purpose of these screening programs is.[9] It is also reported that Deaf people may agree to diagnostic tests and treatments without understanding what the tests comprise, why they are done or what the (side) effect of the treatment may be.[9]

*4) Small community/ need for confidentiality:* The Deaf form a closely knit group and many DHH people often interact socially with other DHH people.[9] Confidentiality is very important.[10] This is why Deaf people may be even more reluctant than hearing people to discuss sensitive topics such as psychological problems or HIV transmission. [10, 11] Fear of isolation from their own community may prevent them from using medical and social services.[10] For non-Deaf healthcare workers it is important to realize that topics that might be considered sensitive among Deaf people, might be different from the topics that are considered sensitive among non-Deaf people.

*5) Respect for Intelligence*: DHH people, including those with mild hearing loses, are often treated as if they are less intelligent. This misconception is partly due to the fact that DHH people may have less medical knowledge than their hearing peers, due to having missed the chance to acquire this through incidental learning. This could be remedied if healthcare workers are aware of this and make sure they offer sufficient information at the appropriate intellectual level.

*6) Dissemination of Information:* When DHH people are approached for research participation the research results are often presented in a way which is incomprehensible to them. Many DHH people are reluctant to participate in research projects, especially when they are run by non-DHH researchers only, because they do not know what their participation may lead to and because they fear of misuse of their data.

These and other barriers contribute to the reduced access to healthcare experienced by DHH people. It is difficult to measure what the extent of the impact of these barriers is, but DHH people have a lower perceived quality of life ($p< 4.13x10^{-14}$) in physical domains compared to non-DHH people. It is conceivable that some of these barriers may have dangerous consequences in acute situations. During our project we found anecdotal evidence that complications occurred during medical treatment due to DHH barriers, but these adverse events are generally not registered.

### ***Research question 3***

The third research question was 'Are there interventions available to tackle these possible barriers and are these cost-effective?'

All healthcare workers and all DHH patients themselves need to be aware of the barriers and work together in reducing them. An extensive search of the literature was conducted to gain a comprehensive overview of current interventions and practices aimed at reducing or removing barriers to healthcare access of DHH people worldwide. In 2016, at least 32 countries worldwide provided structural programmes to assist severely DHH people in medical settings. All 32, including the Netherlands, provided certified sign language interpreters, but it is unknown how many of these countries also provided certified speech-to-text interpreters. Specialized in- or outpatient clinics were present in six countries and advanced ICT facilities were in place to support DHH sign language users in ten countries. Although many of the described interventions might be cost-effective, hardly any research is available to support this hypothesis. Experts and patient groups reported a higher perceived quality of healthcare and a higher perceived quality of health education in specialized healthcare settings. In the Netherlands, until recently, an extensive network of specialized DHH mental health services was available. This may possibly have contributed to the higher perceived psychological quality of life experienced by deaf people in the Netherlands in comparison with deaf people in other countries, but there are no studies available to support these findings. Although it is evident that the needs of DHH patients are not met within regular healthcare practice, and both healthcare workers and DHH patients are enthusiastic about specialized services, insufficient studies are available to support the cost-effectiveness of these services.

## Relevance

This research project is the first inventory of the availability and use of healthcare facilities by DHH people in the Netherlands and one of the first of its kind worldwide. We found that DHH people generally report significantly lower scores on mental and physical quality of life scales than hearing people. Relatively inexpensive measures might be able to reduce these barriers, but the effect of these interventions have not been studied and they are often, depending on the situation, unavailable or underused. The combination of less pre-existing health knowledge with poorer communication between healthcare workers and DHH patients may lead to situations where there may be doubts about whether the relevant ethical standards are met. For instance, the criteria for obtaining informed consent are not always met in this patient group.

It is essential that both healthcare workers and DHH patients become more aware of the health risks encountered by this patient group and learn how to prevent and/or overcome them.

## Implications for future research

The complexity and diversity of the study group makes it difficult and expensive to carry out qualitatively good research. The research described in this thesis is just a start. Since the impact of the barriers encountered by DHH people in accessing healthcare seems to be high, more extensive (inter)national studies are required to gain further insight in this aspect. The barriers encountered in healthcare provision for DHH people are similar worldwide: The same types of language, communication and cultural barriers are present. This makes allows for collaborations in research and extrapolate research on healthcare barriers in Western countries, or even worldwide.

Specific health problems encountered by DHH people and the detection/ prevention thereof, is not covered by the research in this thesis. Studies into these problems are just emerging. Two types of specific health problems of DHH people are expected to be present. The best known are the co-morbidities directly related to the cause of the hearing loss. If healthcare workers are aware of the cause of the hearing loss, they might be able to prevent or detect these comorbidities at an early stage. Less known are specific health problems that are unrelated to the cause of hearing loss. It is generally known that many ethnic/ cultural groups have their own specific health risks. Since some DHH people form their own linguistic and cultural minority groups, it can be expected that they also may have a specific health profile. Some recent studies hint at the existence of a specific health profile for DHH people. More research on the extent and nature of these health problems is needed before prevention or early intervention is possible. The barriers encountered in healthcare provision for

DHH people are similar worldwide: It can be debated whether this is also true for the specific healthcare problems experienced by DHH people. Some of the specific health problems may intersect as the result of similar health barriers, but it is possible that local differences exist. There is not enough scientific research available to make evidence-based statements on this.

While many local attempts are made to improve healthcare access for DHH people, very few studies have been published on the advantages, disadvantages and/ or costs-effectiveness of these interventions. All these interventions and attempts should be evaluated, monitored and reported structurally.

**Recommendations:**

People who are Deaf or Hard of hearing face health risks, just like non-DHH people. Besides these health risks, they encounter barriers in accessing healthcare and may face specific DHH-related health risks. DHH people themselves need to be aware of the preventive healthcare possibilities and the implications of diagnostic and therapeutic possibilities. This is a basic prerequisite for ethical medical practice.

The barriers encountered in the provision of healthcare for DHH persons are similar worldwide. Specialized DHH healthcare workers have thought for a long time (and still think) that similar interventions to improve healthcare access could be used internationally. Based on the results of section 5.1 and 5.2 we think that strategies to successfully overcome the barriers depend mainly on the local situation. The following recommendations are based on current knowledge, and are divided into universal and local (Dutch) recommendations.

<u>Universal recommendations:</u>

1) Create awareness of the needs of this patient group among healthcare workers.

DHH people are a distinct patient group with specific linguistic, communication and sometimes also cultural needs. In this respect they are comparable to other minority groups. In many Western countries healthcare workers are trained in how to communicate with, and provide medical care for, linguistic, cultural and ethnic minority groups. They need to become aware that similar skills are necessary when treating DHH people.

2) Create awareness among DHH people themselves.

DHH people are a distinct patient group who face communication and sometimes also cultural, linguistic and medical barriers that prevent them from receiving optimal healthcare. Access to general health information and specific patient information should be improved. Despite technological developments, such as advanced hearing aids and cochlear implants, an education program addressing DHH people, including children, adults and the elderly is needed. This should be aimed at improving their knowledge about how their own body functions and provide insight into the etiology, consequences and treatment options of specific diseases. Even with the use of modern technological aids DHH people miss out on incidental learning about medical and health matters as they cannot hear well in noisy surroundings nor overhear conversations on these topics. As long as these barriers are not resolved, ongoing education programs are needed.

3) Any plans for a facility, service, healthcare provision, practice, ICT-service or other project to improve DHH healthcare access should comply with local DHH needs and be developed in close collaboration with the target group(s). This means that both the healthcare workers and the diverse DHH group(s) must be involved. These patients with complex needs deserve professional and excellent healthcare provision. This implies that the best of both worlds is needed: the best specialized healthcare workers in the indicated (medical) field, who join forces with the best communication specialists and DHH experts.

Local recommendations:
In 2014 a specialized outpatient clinic following an Austrian model, was set up in the Netherlands. One of the reasons that this initiative failed is that the local situation in the Netherlands was not taken into account. Low cost specialized healthcare is necessary to meet the needs of DHH people in the Netherlands. Initiators must realize that the number of consultations on a yearly basis will be low but the impact of such specialized healthcare provision is high. The following possibilities should be considered:

1) Improved ICT-facilities to support regular healthcare facilities. 2) Creating a national center of expertise that collects information on existing DHH healthcare knowledge and makes it available for healthcare workers and DHH patients. Additionally, the center could coordinate the education of both healthcare workers and DHH people themselves. Such a center of expertise should combine all the existing expertise by collaborating with all existing DHH organizations. At the same time, if it is to be successful in the Netherlands, the center of expertise must be independent of the existing organizations.

3) Ideally this center of expertise will also be able to organize medical consultations. A cost-effective way to achieve this might be that the center of expertise organizes a team of experts (derived from various organizations) to carry out the consultation, depending on the situation and consultation question.

## Epilogue

Viewing DHH healthcare provision from a social model is a complex and beautiful research area. It is challenging but extremely interesting to work in this relatively new research area.

Eleven years after my train ride, many of the basic DHH health research questions have been answered. I hope that this doctoral dissertation will be an inspiration to funding authorities and researchers so that in eleven years from now, a solid scientific foundation for a 'social model' of DHH health research will be available.

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