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

Anika S. Smeijers

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The work reported in this thesis is part of the ZorgBeter-project. The ZorgBeter-project was financially supported by the Dutch foundation for disabled children (NSGK- voor het gehandicapte kind) and the Handgebaar foundation.

The printing of this thesis was sponsored by:
Landelijk Expertise Centrum Kindermishandeling (LECK) and Specsavers.

AVAILABILITY AND ACCESSIBILITY OF HEALTHCARE
FOR DEAF AND HARD OF HEARING PATIENTS
PhD Thesis, University of Leiden, The Netherlands

Cover design and layout: © evelienjagtman.com
Printing: proefschriftmaken.nl

ISBN: 978-94-6380-466-0

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

Proefschrift

Ter verkrijgen van de graad van Doctor aan de Universiteit Leiden,
op gezag van Rector Magnificus Prof. mr. C.J.J.M. Stolke,
volgens besluit van het College voor Promoties
te verdedigen op dinsdag 15 oktober 2019
klokke 15.00 uur

door

Anika Susanne Smeijers

Geboren te AMSTERDAM in 1980

Promotores
Prof. dr. H.M. Oudesluys-Murphy
Prof. dr. E.M. van den Bogaerde (Hogeschool Utrecht & Universiteit van Amsterdam)

Co-promotor
Dr. M. H. Ens-Dokkum

Promotiecommissie
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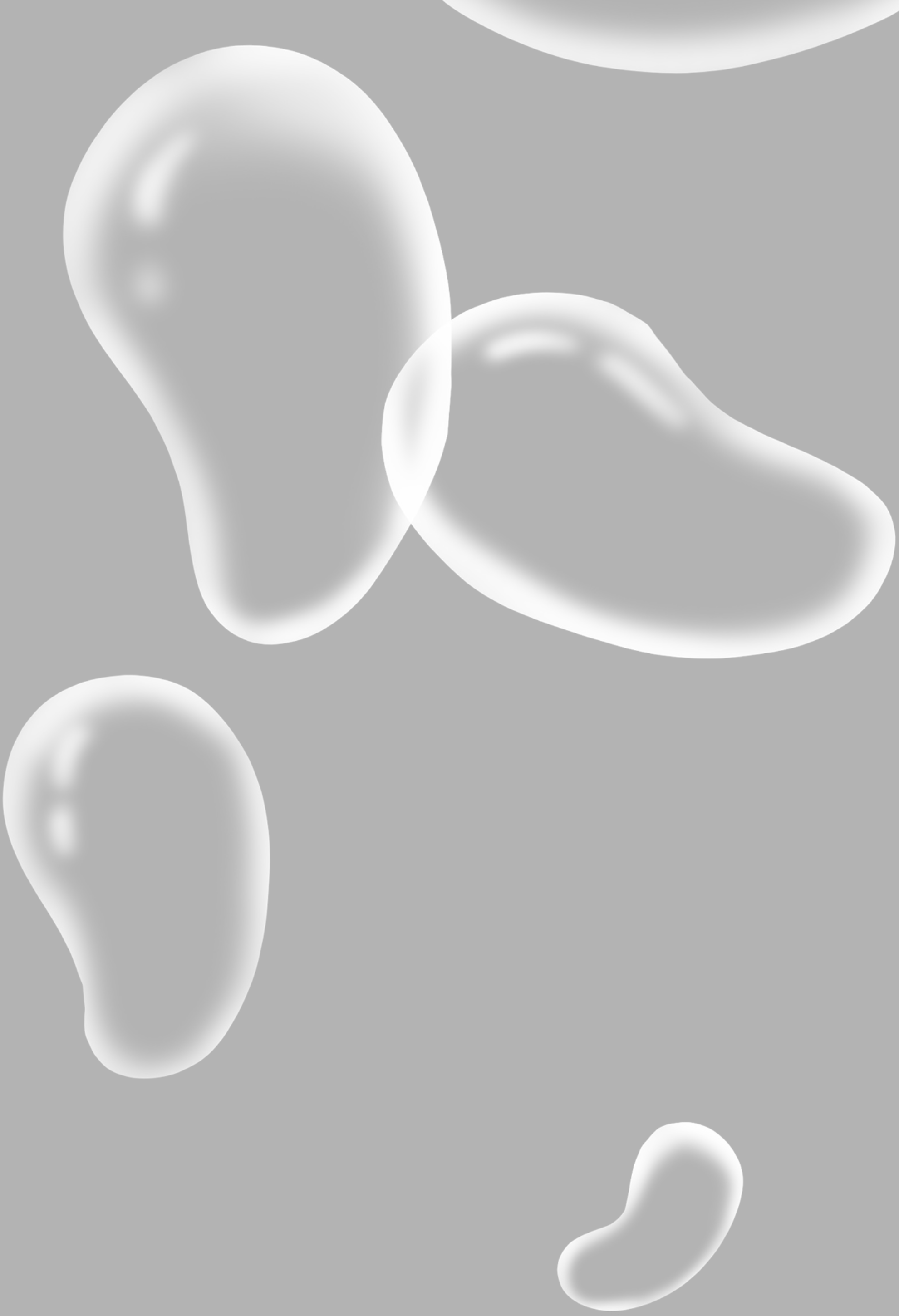
Prof. dr. R. Reis

The ZorgBeter-project, of which most of the studies presented in this thesis are part, was approved by the Medical Ethics committee of the Leiden University Medical Center.



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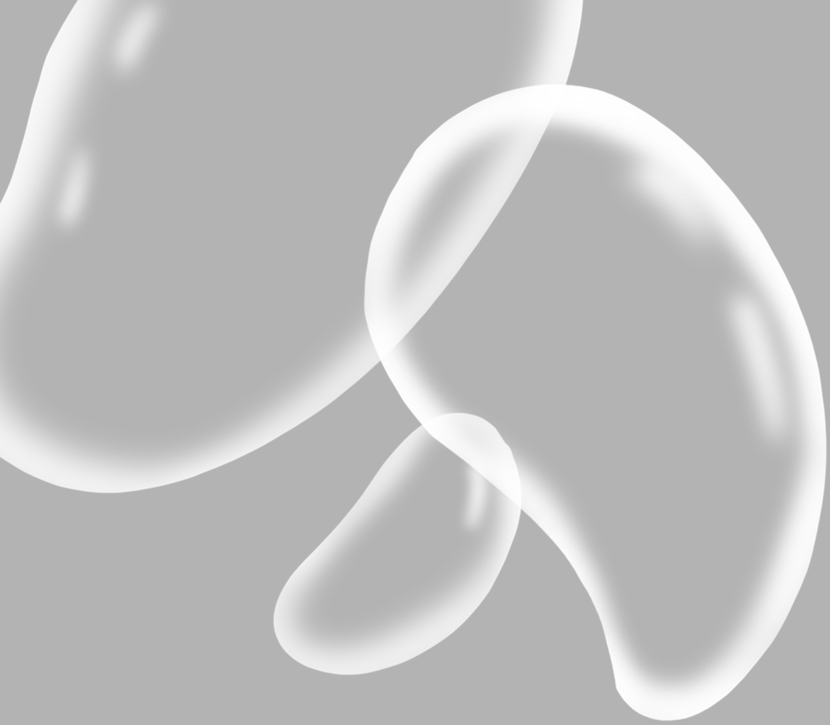

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Introduction and outline of this thesis

Introduction and outline of this thesis

Autumn 2002, I am attending a play by the ´Handtheater´ company with my fellow students. This theatre company uses Sign Language of the Netherlands (NGT) as the official language of their shows. It is a busy evening, the theatre is sold out, and nobody seems to feel like going home afterwards. Drinks are bought, and people are gathering together to discuss the play. My fellow students and I are new to this scene; hesitant to start a conversion with someone we do not know, but eager to put our newly acquired skills as NGT students into practice. Suddenly the person next to me signs to me ´I don´t know you, are you studying to become an NGT interpreter?' I introduce myself and explain that I am a medical student who is learning NGT. She smiles at me, turns around and continues her conversation with one of the other persons present. A good-looking guy approaches me and the same short conversation was repeated (although I would have loved to chat with him a bit longer). After this I decide to enjoy my drink and observe, while my fellow students have animated conversations with new acquaintances. This conversation pattern repeats itself in the following weeks when we attend other plays, NGT festivals and an NGT symposium. By the end of the semester my fellow students got to know quite some people within the Deaf community while I am still mainly enjoying my drinks and making observations. I decide to discuss my newly discovered social handicap with one of the Deaf NGT teachers. She explains to me that the problem I perceive is completely clear to her: ´Every Deaf person knows that medical doctors are impossible to communicate with, so why even bother trying to communicate with a medical student? Just stop telling everyone that you are training to be a doctor, say you are an NGT student.´ Her advice worked perfectly. Fifteen years later I have many friends and acquaintances within the Deaf community. But a little seed was planted which led to this thesis….

Epidemiology

Mild or severe hearing loss is not a rare disorder, its prevalence increasing with age from around one per 1000 at birth to 1.6 per 1000 in adolescence, and to 88 per 1000 at age 65. In this project we mainly focused on the group who were, or became, severely deaf or hard of hearing (DHH) at a young age. There is no linear correlation between how persons who are DHH function in daily life and their degree of hearing loss in decibels, or with the type of hearing aids (such as amplification and cochlear implant) they use. Their functioning depends on a complex blend of interacting internal and external factors.

Internal factors vary per individual, e.g. cause of the hearing loss, time elapsed since hearing loss occurred, severity of hearing loss (mild, moderate or severe), progression of hearing loss over time, comorbidities, visual/intellectual and social functioning. External factors may vary as well. Important external factors are quality and duration of audiological, psychological and communication interventions, the availability of local and national facilities for DHH people, including education and mode of communication (spoken language, sign language or sign supported spoken language) used by parents and other carers.

Various ways to categorize severity of hearing loss are described in the literature (chapter 2). In this thesis 'DHH' is used to describe anyone with any degree or type of hearing loss. The term 'severe DHH' is used to describe people who experience difficulties in understanding a spoken conversation without using visual support.

Language development and sign language

Sign languages have complex grammatical structures which allow access to information in a natural way and expression of opinions, desires and abstract thoughts.[1] Full access to a high quality and a sufficient quantity of a natural language is essential for the developing brain (neurolinguistics) and for adequate language development of all children. The reduced access to spoken language of people who are, or become DHH at a young age, may interfere with their ability to develop language skills. When access to spoken language is limited, a sign language can ensure full language access. Full language access enables children to develop not only semantic and grammatical language skills (e.g. what a word means and how to conjugate a verb), but also social and pragmatic skills (how to use intonation, intermission, turn taking, interpret double meanings, etc.). A frequent misconception is that severely DHH children and adolescents are able to develop full language skills through reading and writing. This might be true for semantic and grammatical language skills, but many other language skills can only be learned during interpersonal communication. On top of that, the reading and writing abilities of people who become DHH at a young age may be limited. An alphabetical writing system is used in most countries. In these, phonemes (the sound of characters, like 'a', 'e', or 'm') are directly linked to the grapheme (the letter). This is an easy to learn system for people who have acquired spoken language, but people who cannot hear the phoneme have to memorize which combination of characters, and in which order, are used for a certain concept. This means that they are able to fluently read only those words that they have read before and of which they have memorized the character construction.

Accessibility of healthcare for DHH people

Healthcare workers and patient groups commonly report that people who are DHH have a poorer health related quality of life than hearing people. The reason most frequently put forward is that DHH people experience barriers in accessing healthcare. This has substantial consequences for their health and wellbeing. Several authors have described barriers that may have a negative impact on the health of DHH people.[2] These barriers may vary, depending on residual hearing, the age of onset of the hearing loss and the degree to which the individual accepts and uses available support such as amplification, sign language interpreters or speech to text interpreters. Possible barriers that have been described so far in the literature are: a) Communication barriers, b) Barriers due to reduced medical knowledge and c) Deaf cultural or Deafhood barriers. No quantitative studies have been done so far to explore the nature and impact of these possible barriers. This thesis aims to fill this gap. The results may help to improve DHH healthcare accessibility and hopefully inspire future DHH patients and medical doctors to communicate successfully together.

a) Communication barriers.

DHH people may encounter communication barriers during medical consultations. This is particularly the case when DHH people do not have enough residual hearing to fully hear and understand spoken language. Many DHH people rely on a combination of hearing and lipreading for understanding spoken language. Even a highly skilled lip-reader is able to 'read' only 20-40% of what is said.[3] This suffices to follow a fairly predictable conversation in normal everyday circumstances. However, during a medical consultation, when many unknown terms are used and the patient may be stressed, this method often proves to be inadequate.[4,5] Even if the healthcare worker writes down the necessary information during a consultation, this may not be very helpful. If the patient is severely DHH from a young age, he or she may have difficulties reading uncommon or unfamiliar words. Even when the DHH person is able to understand written language fluently, writing down information is much more time consuming than talking, which results in healthcare workers writing down only a small portion of the information normally given.

The use of speech-to-text interpreters and/or sign language interpreters in medical settings may help overcome these barriers. These possibilities are not always known or used. The amount of information transferred from the physician to the patient and vice versa is therefore restricted.[6] Next to misunderstandings and reduced information, communication barriers may also pose logistical problems, for instance, making an appointment or asking for a repeat prescription; instead of being able to contact the physician's office by telephone it may be necessary to go there in person.

b) Barriers due to reduced medical knowledge

DHH people often acquire less medical information, less information about their own body, about health and feelings than non-deaf people. Compared to hearing people, they may know less about what to expect during a medical consultation or during hospitalisation and may have less insight into what information is relevant for the doctor. Three factors contribute to this lack of knowledge. The first of these factors is the lack of implicit learning opportunities. A large amount of health information is discussed by hearing people during informal conversations. Children and adults learn from overhearing these exchanges. DHH people do not have access to this type of ambient information and therefore miss out on acquiring this information.[7-9] The second factor is reduced access to explicit learning, e.g. formal education, information evenings, debates, news programs on television and radio and government information. In the Netherlands DHH people often have only limited access to these information sources. Availability of sign language (SL) interpreting and speech-to-text interpreting is limited. [4,10] The third factor is that people who are severely DHH from a young age may be less able to access, look up and fully understand the internet or other written sources of information due to limited reading skills.

c) Deaf Cultural or Deafhood barriers

Some of the people who are deaf or hard of hearing from a young age and who use sign language as their primary mode of communication, consider themselves members of the Deaf community. Deaf communities constitute a social and linguistic minority within the majority ‘hearing’ culture.[11-13] These communities have their own norms and values. In order to distinguish between the clinical meaning of the term *deaf* and the cultural meaning of *Deaf*, we adopt the convention of referring to the latter with a capital *D*. Communication problems between members of such a community and hearing healthcare workers may lead to misunderstandings due to Deaf Cultural barriers.

Organizations of DHH people state that their members often report negative experiences in their contacts with the medical world. These experiences begin during childhood when they are regularly brought to medical practitioners, including General Practitioners (GPs), paediatricians and audiologists, without adequately understanding what is happening to them and why. The negative experiences are reactivated in adult life when they feel that they do not receive or understand information from healthcare workers.

The extent of these barriers and the risks they pose to the health of the people involved are unknown. We formulated three research questions to gain more insight into this situation:

1) Do deaf or hard of hearing people experience more barriers when they try to access healthcare facilities than people who are not DHH?
2) What is the nature of these possible barriers and how large is their impact?
3) Are there cost-effective interventions available to tackle these possible barriers?

Outline of this thesis

Section 2 introduces the communication challenges and medical, ethical and legal issues that a physician can face when providing care for DHH children and children of DHH parents.

Section 3 is a methodological chapter. It describes the steps involved in providing standardized questionnaires and some of the methodological challenges we faced. It describes the theoretical background, development and use of a guideline to translate and validate standardized questionnaires into sign language.

Sections 4 and 5 describe our research results. In **Section 4** the nature and impact of barriers in healthcare access for DHH people are studied and discussed. **Section 4.1** describes the results of our pilot study where we explore the communication between 32 severely DHH patients and their general practitioners. **Section 4.2** describes the quality of life of deaf and hard of hearing adults in relation to the extent of their hearing loss, language skills, their relation to the Deaf community and cultural features. **Section 4.3** focuses on the Deaf cultural barriers that DHH people encounter when they need to access the healthcare system.

In **Section 5** we study and discusses possible services and facilities that may help to improve the health of DHH people. **Section 5.1** describes the services and facilities that are used world-wide to facilitate this patient group. In **Section 5.2** we evaluate the start-up and closing down of a specialized outpatient clinic for DHH in the Netherlands.

In **Section 6** we present the general conclusions and discussion.

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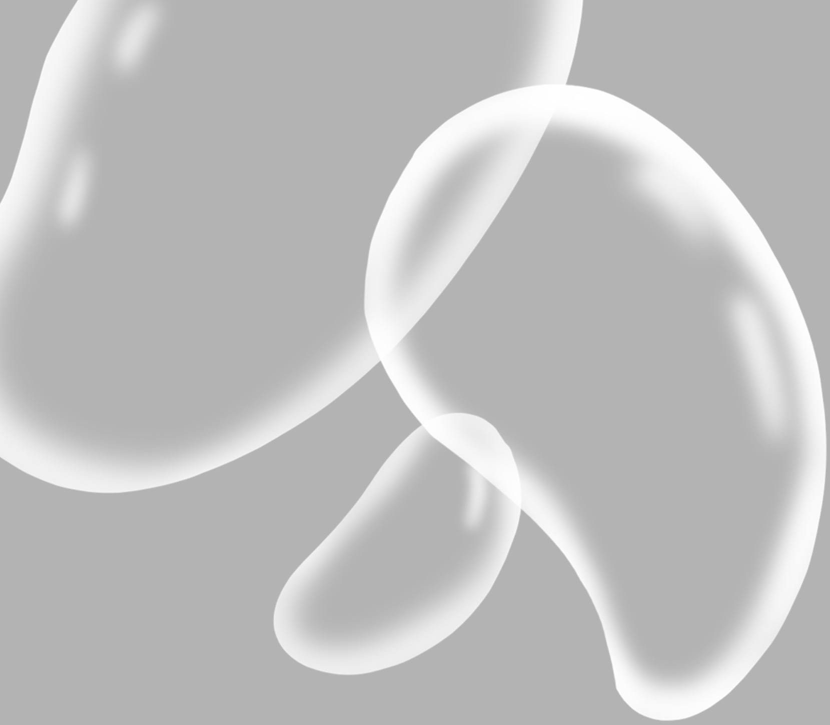

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The approach to the deaf or hard of hearing pediatric patient

Published article:

Smeijers AS, van den Bogaerde B, Ens-Dokkum MH, Oudesluys-Murphy AM, Clinical Practice: The approach to the deaf or hard of hearing pediatric patient. European Journal of Pediatrics. 2011;170: 1359-63

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 severly 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[7,8].

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 audiologic 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[13]. 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[9,11,12]. 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[14]. 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[1].

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[5,10]. 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[2] and often report a lower quality of life on social domains[3,15]. 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[6].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 [4]. 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 therefor 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
Netherlands: www.gezondecomunicatie.info
United Kingdom: 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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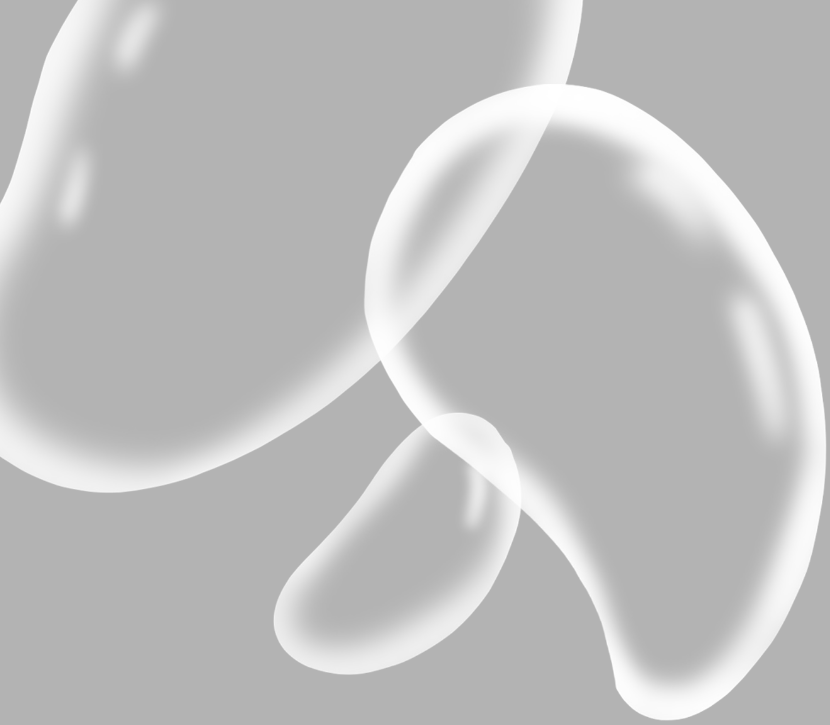

3

Scientific-Based Translation of Standardized Questionnaires into Sign Language of the Netherlands

Published book chapter:

Smeijers AS, van den Bogaerde B, Ens-Dokkum MH, Oudesluys-Murphy AM, Scientific-Based Translation of Standardized Questionnaires into Sign Language of the Netherlands. In: Investigations in HealthCare Interpreting. Nicodemos and Metzger, editors. Gallaudet University Press, Chicago 2014:277-301

Abstract

Specialized psychological and psychiatric healthcare for deaf and hard of hearing clients has emerged during the last 50 years. It has long been known that deaf and hard of hearing clients are often misdiagnosed with psychiatric disorders, but little scientific attention has been paid to the tests used with this group. Although these clients may have poor spoken language skills and a different (cultural) background from mainstream clients, regular diagnostic tests are used, even in specialized settings.

To enable the use of standardized questionnaires without language barriers, we have developed a guideline for adapting internationally validated questionnaires and translating them into sign language. We used this guideline to adapt and translate four questionnaires into sign Language of the Netherlands (Nederlandse Gebarentaal, NGT). In this chapter we will introduce our guideline and describe the selection and translation process of research instruments for use with deaf and hard of hearing individuals. The problems, dilemmas and ethical issues encountered are discussed.

Introduction

One in a thousand people worldwide is born deaf or severely hard of hearing (Kennedy & Mc Cann, 2004) and this number increases with age. These children face many challenges in acquiring the spoken and written language of their environment. Many of them have great difficulty in achieving a literacy level comparable to that of their peers (Musselman, 2005). One of the reasons for a prevalence of low literacy among deaf people, is that many Western languages have an alphabetical writing system (consisting of letters or graphemes) that is based on phonemes. Phonemes are the sounds, e.g. vowels, consonants, of a language that change the meaning of words (e.g. *hat* versus *bat* [h-b distinction] versus *hit* [a-i distinction]. When you cannot hear these phonemes, you have to memorize for - all words- which letters/ graphemes represent them, (e.g. what combination of characters and in which order they are used for a certain concept). An English example would be the verb “know”, of which the visual image on the mouth resembles the pronunciation of the word “no” – these two written forms of the sound [no] thus need to be explicitly learned. Deaf people also cannot automatically use vocalizations when reading. This means that deaf people are able to read fluently only those words that they have read before and whose written graphemic construction they have memorized.

For many deaf and hard of hearing individuals a sign language is their natural language, because they have full access to it. In the Netherlands, Sign Language of the Netherlands (Nederlandse Gebarentaal: NGT) is used. In contrast to certain other sign languages like American Sign Language and Flemish Sign Language, NGT up to now has not been recognized by the Dutch government as an official language of the Netherlands.

Over the past 25 years there have been discussions about whether deaf people have more in common with each other than just their medical condition (*in casu* their hearing status) plus the fact that many of them are sign language users. Researchers from Great Britain (Ladd, 2003) and the United States (Padden & Humphries, 1988, 2005) have convincingly defended the existence of a Deaf culture. These studies show that the Deaf communities constitute social and linguistic minorities within many Western hearing cultures. Such a Deaf cultural minority is characterized by shared experiences, values, traditions, behavioral rules, and, most important, the use of a sign language as the main mode of communication. Having a cultural identity different from that of the majority in society may have a negative effect on communication and healthcare provision (Van Wieringen, Harmsen & Bruijnzeel, 2002). To distinguish between the audiological concept of deaf and the cultural Deaf, a capital letter is used for the latter. The designation “Deaf” is used here to include people who see themselves as culturally

Deaf and as belonging to a linguistic minority group. The designations "deaf" and "hard of hearing" are used here for people who developed a hearing loss, including Deaf, deaf and hard of hearing.

In the Netherlands, as in many other Western countries, there are limited facilities for Deaf people to ensure their full participation in the wider society. For instance, sign language support by interpreters is restricted, and medical information in NGT is scarce. In contrast to the United States, we in the Netherlands do not have a disability act. An international UN convention handles the rights of people with a disability but the Dutch government has not yet ratified this convention. These aspects, together with lack of access to the spoken language (e.g. no incidental learning), explain why deaf and hard of hearing individuals often have less general and medical knowledge than hearing people (Barnett, 1999; Jones, Renger & Firestone, 2005; Vernon & Andrews, 1990).

Mental healthcare

Little information is available on the impact of cultural and linguistic barriers on the medical care offered to and received by deaf and hard of hearing individuals (Smeijers & Pfau, 2009; Van Wieringen et al, 2002). The incidence of psychological problems is higher among these individuals than among the hearing population (Fellinger et al., 2005b, 2007). This is partially explained by the fact that people with severe hearing impairment often face social barriers due to communication problems. Another explanation is that this might be a result of the two to three times greater prevalence of sexual abuse (possibly due to communication barriers and poorer social skills) in this group than in the hearing population (Hoem Kvam, 2004).

The incidence of psychiatric disorders in deaf and hard of hearing individuals is an important subject of discussion in the medical literature. In the 1950s deaf and hard of hearing individuals in the United States were relatively overrepresented in psychiatric clinics (Pollard, 1994; Stein, Mindel & Jabaley, 1981). These findings ultimately led to the development of specialized mental healthcare for deaf and hard of hearing patients. Within these specialized settings extra attention is given to the patients' cultural background and language skills. After the transfer of patients to these specialized facilities, it became evident that many of them had no psychiatric disorder. Some had a mild cognitive impairment, and some had a severe language impairment caused either by weak language skills, first-language deprivation, or a primary language disorder. Although non-specialized clinics still report a higher incidence of psychiatric disorders within the deaf and hard of hearing population, no evidence for this has been found in specialized settings (Pollard, 1994). Since the emergence of specialized healthcare facilities for deaf and hard of hearing individuals is only recent, the number of research instruments especially developed for or adapted to deaf and hard of hearing individuals is still low.

Psychological tests

Psychological testing of deaf and hard of hearing sign language users is usually done via written questionnaires. However, as explained earlier, using the written language of the hearing minority may be problematic in this population because its members have an inadequate mastery of local spoken/ written language (Musselman, 2005). More often than not these questionnaires are translated ad hoc by sign language interpreters, because very few test instruments are available in sign languages (Munro & Rodwell, 2009). If an interpreter interprets a written questionnaire ad hoc into sign language the interpreter may make non-standardized linguistic and cultural adaptations. Such adaptations can of course influence the replies to the questionnaire and thus the general outcomes. In most situations the interpreter will also interact with the deaf or hard of hearing test participant who is filling out the questionnaire. A common pitfall is that the results of questionnaires that were administered by ad hoc interpreters are analyzed as if they are standardized questionnaires, while the questionnaire was actually converted into a sort of interview.

Research on ethnic minority groups has demonstrated that the mental and physical well-being of the group members is influenced by their cultural identity (Guillemin, Bombardier & Beaton, 1993). Therefore, health-related quality of life (HRQoL) questionnaires can be used for people whose linguistic and cultural identity are different from that of the original target group only *after* an accurate process of translation and cultural adaptation (Guillemin et al, 1993; Hocker, 2010). Furthermore, online surveys that use a recorded sign language translation of a written questionnaire are more suited to reach deaf persons (Graybill et al, 2010; Hocker, 2010). However, as far as we know, only one adapted and translated HRQoL questionnaire for deaf people exists, and this instrument is in use in Austria (Fellinger et al, 2005a). A limited guideline is available on translating questionnaires into sign language (Crowe, Mason, 2005). However, we could find no comprehensive guidelines that cover the whole process of translating and adapting the questionnaires for use by deaf and hard of hearing respondents. When we planned to conduct an epidemiological study on the health and healthcare needs of deaf and hard of hearing individuals in the Netherlands, we became aware of the enormous problems posed by the lack of suitable instruments for this group. To help solve these difficulties we developed guidelines that we adapted during the process of translating four questionnaires into NGT for our research project.

Methodology

Procedures

Founded on current guidelines for translating and adapting HRQoL questionnaires for spoken languages (Hocker, 2010; Pollard, 1994; Ravens-Sieberer et al., 2005; The KIDSCREEN Group Europe, 2006) and referring to our own trials and experiences, we have developed guidelines for translating international written questionnaires into a sign language (Figure 1). A group of Deaf NGT communication experts, a physician/NGT linguist, a second NGT linguist, NGT interpreters, and a master's student in Deaf studies translated the selected questionnaires into two different variants of NGT. After backward translations (i.e. from NGT into written Dutch), consultation between experts and reviews by deaf and hard of hearing test participants, the signed questionnaires were adapted to the cultural and linguistic needs of deaf and hard of hearing individuals.

Besides the two NGT versions, a sign-supported version (spoken Dutch with simultaneously produced NGT signs) and a written Dutch version were also provided. All of the questionnaires were placed in a secure online environment. We used Unipark software, which allowed us to create our own layout and has a direct link to a database (Hocker, 2010; Unipark, 2015). The guidelines are presented in appendix 1 while their development is discussed in this chapter.

Instruments

One of our first challenges was to select test instruments that were suited for translation into NGT and that were reliable also when used by people who have weak language skills and minority cultural backgrounds. The selected questionnaires for this study are as follows:

- *World Health Organization Quality of Life-BREF (WHOQoL-BREF):* This is an internationally standardized questionnaire that has been translated and validated in more than a dozen languages and has been widely field-tested, which makes the instrument methodologically strong (WHOQoL Group, 1998). Numerous questionnaires have been designed to measure all sorts of aspects of quality of life. Quality of life questionnaires that explicitly evaluate participants' physical health are less common. We chose the WHOQoL-BREF because it was the only short questionnaire that met both our content demands and our methodological demands.
- *General Health Questionnaire (GHQ)*: This is a screening instrument to identify minor psychiatric disorders. It can be used in the general population or with clients in non-psychiatric clinical or primary care settings. We have used the GHQ-12, the shortest version especially designed for research studies (Goldberg & Williams, 1988). One of its strong points is that it is a short, reliable questionnaire.

- *KIDSCREEN:* This is a generic quality of life instrument that has been designed and normed for (hearing) children and adolescents between the ages of 8 and 18 years. KIDSCREEN can be used as a screening, monitoring and evaluation tool in health surveys (Ravens-Sieberer et al., 2005; KIDSCREEN Group Europe, 2006). It covers ten health-related quality of life dimensions, whereas many QoL questionnaires for children cover only psychological and schooling domains. It is an internationally standardized questionnaire that does not require a high language level.
- *Deaf Acculturation Scale (DAS):* This is a 58-item scale that measures deaf and hard of hearing individuals' degree of acculturation to both Deaf and hearing cultures. It consists of two overall acculturation scales: a Deaf acculturation scale (DASd) and a hearing acculturation scale (DASh). Both measure acculturation in five domains (Maxwell-Mc Caw & Zea, 2011). The DAS is the only validated international scale that provides information about the cultural status of deaf and hard of hearing individuals. Having a cultural identity different from that of the majority in society may have a negative effect on an individual's communication (Van Wieringen et al, 2002). The DAS can be used to evaluate such effects among deaf and hard of hearing individuals.

Issues encountered during selection and translation of questionnaires

Our project consisted of five phases: 1. choosing the questionnaires; 2. producing the forward translation; 3. producing the backward translation and harmonization; 4. testing; 5. taking the survey. We encountered linguistic, cultural and technical issues during all phases of selection and translation of questionnaires. Later we describe these issues and how we dealt with them.

Selection criteria for questionnaires

It is difficult to perform a validation study on questionnaires to be used by sign language users because of the small number of such persons in the population, as mentioned earlier. Therefore, one has to be very sure of the potential and the characteristics of the questionnaire. We preferred to use only internationally validated questionnaires that already had been successfully translated into a number of languages and have been used in various cultural settings, not questionnaires that were validated in only a limited number of European countries or the United States only. From those we chose the ones that showed the most potential for cultural and linguistic translation. For instance, questionnaires that use a great deal of figurative speech are more difficult to translate into another language, as are questionnaires with many semantic weaknesses (see example 1). We also took the required language level into account. Since the medical knowledge of deaf and hard of hearing individuals is often limited, we excluded questionnaires that use a large proportion of medical jargon or require a high language level.

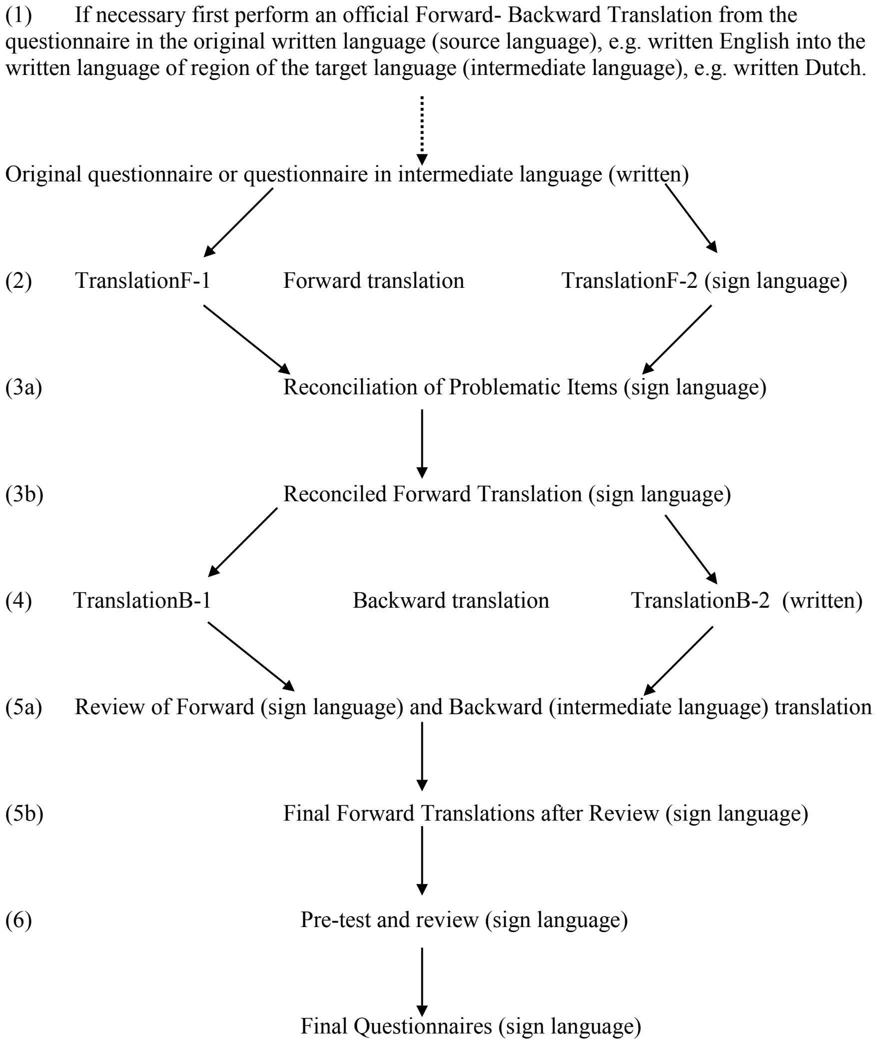

Figure 1: Guidelines for translating questionnaires into a Sign language

Example 1 (from GHQ)

Have you felt capable of making decisions about "things".

"Things" is semantically weak and therefore a difficult concept to capture in translation.

Selecting Signers

The main but elementary difference between a written questionnaire and a signed one is the need for a signing interviewer on the screen. The person who is recorded signing the questions, will automatically function as the interviewer. As with any interviewer, this individual may cause some bias. To minimize the bias, the signers must be carefully selected.

A central point in this is that the respondent to the questionnaire must feel comfortable with the signer, who may be asking very personal questions. Although the respondents will be aware that the signer on the film will not see the answers, the signer will unconsciously exert influence nonetheless. Interviewer bias can also be caused by gender, age, status, cultural and ethnic background, language and/or linguistic style.

To minimize potential bias, we decided to make different versions. One version was signed by a deaf woman who is a teacher of NGT and Deaf culture and is well known in the Deaf community. The second version was signed by a hearing male NGT interpreter who has much experience in working in psychiatric settings but has no personal attachments to the Deaf community. In the Netherlands the Deaf community is rather small, and most of its members know each other. By choosing one interviewer who was well known in this community, we created an opportunity for the participants to be questioned by someone familiar and trusted. By also selecting an NGT interpreter without personal attachments to the Deaf community and who works in a small, specialized setting, we provided an opportunity for the respondents to be questioned by an unfamiliar, more neutral person. In addition, NGT has five regional variants, all of which are mutually understood by native signers. For educational reasons, a standard version of NGT's most basic lexicon was introduced in the 1990s and is firmly established today. The two signers of the questionnaire came from different parts of the country. They were both instructed to sign in as standard a manner as possible, but they did so with a slightly different NGT accent.

Two-thirds of the participants in the end chose the Deaf woman as the sign model. This model also resulted in fewer respondent drop-outs than with the male interpreter as the sign model. This supports our hypothesis that the current practice of using ad hoc, non-cultural Deaf sign language interpreters to administer non- culturally adapted tests may cause bias and a false sense of feeling that the participants' needs are sufficiently met.

Adaptations in translating the questionnaires

While translating the questionnaire, one must understand both the underlying reason for the questions and the frame of reference of the target group related to them. One of the issues that we encountered during translation was that the items on some questionnaires are written in the first person, for example, "I feel sad." This is done to encourage the participant to internalize the item. Since sign language is a visual language, an interviewer will always be present. If a question is written in the first person, the interviewer will always have to use a form of direct speech (i.e., the interviewer will point to himself while asking the question). It is arguable whether with the original purpose of first-person use, more internalization of the question is reached in this situation. We found that second person (e.g., signer points at respondent [= viewer] while asking the question [e.g., "Do you feel sad?"]) is a more direct and more suitable form for sign languages. Therefore we adapted the first-person phrases, for example, in some of the questions in the American DAS questionnaire (see example 2).

Example 2. (from DAS)

Original question	***Adapted question***
I call myself Deaf (yes/no) ->	Do you call yourself Deaf? (yes/no)

One of the questions that was adapted for person.

An example of cultural issues during translation was the question "Are you a member of a club or society?" (yes/no). The purpose of this question is to test social involvement, but it was placed between mainly medically oriented questions. Within a hearing population this will not cause any problems, but within the Deaf community, lobby groups and associations of Deaf or hard of hearing persons are often also seen as clubs or societies. We transferred the question to the section where other social questions were asked and added the word "socially" to avoid "yes" answers when the respondent was actually not socially active ("Are you a member of a socially active club or society?").

Technical issues of translation.

Our questionnaires consisted of 151 questions. This meant that, including formal introduction and instructions, we had to translate 170 items. We estimated that it would take approximately 8 hours to produce the first forward sign language translation (translationF) and 4 hours to film the adaptations. We expected the backward translation (translationB) to take 2 hours. For the production of the sign-supported version we reserved 4 hours. Our estimations for the sign language version turned out to be very accurate.

Although no full translation had to be made, it turned out that it is as time consuming to film a sign-supported version as it is to produce a sign language version. In our case we also used a signer who was not accustomed to being filmed, which possibly caused some extra delay. It took a total of 12 hours to film the first sign-supported version.

For all of the recordings on different filming days, the signer has to wear the same clothes, which should be neutral in color but contrasting with the background. When the camera is positioned, one has to make sure that the whole signing area (picture) is captured. The signer's hand should not go outside the filmed area, not even during breaks between contiguous sentences. Moreover, the signer must always look directly into the camera. Often a helper will be standing next to the camera or a text will be put up next to the camera; an autocue can be used. When the signer looks at this person or the text during the filming, the signer's eye direction changes, which may have grammatical consequences in most sign languages. Since "person" in NGT, like in most sign languages, is expressed by pointing at a certain locus (localization[1]) the question will seem to be directed to a third person rather than to the viewer/participant (second person).

Presentation

Since sign language is a visual language and deaf and hard of hearing individuals are visually orientated, it is imperative to give special attention to the layout of the recordings and how the films are presented online (Baker et al., 2008). The combination of yellow and blue is known to be the most comfortable to read with the best contrast, therefore we choose a light yellow background and a dark blue font. We placed the movie with the NGT question in central position on the screen because this is the most important item. To create a lay-out which would be familiar we placed the written text below the films on the screen, as in subtitles. A bar at the top of the screen shows the participant what percentage of the questionnaire they have filled out (Figure 2).

When answers were only short phrases (e.g. *yes/no/don't know*), these could be provided in writing only because when several films are placed on one screen the overall view is reduced and it takes a great deal of viewing time. Although using NGT instead of written text improves understanding in Deaf respondents, it is also more time consuming to look at movies than to read. When the answers are only short phrases, these side effects compromise the positive effect of NGT on comprehensibility.

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[1] Localization refers to pointing to a specific place in space, whereby the pointing acquires semantic meaning, (e.g. "first person" is pointing at yourself, while "second person" is pointing at the interlocutor or at the space directly in front of to the signer).

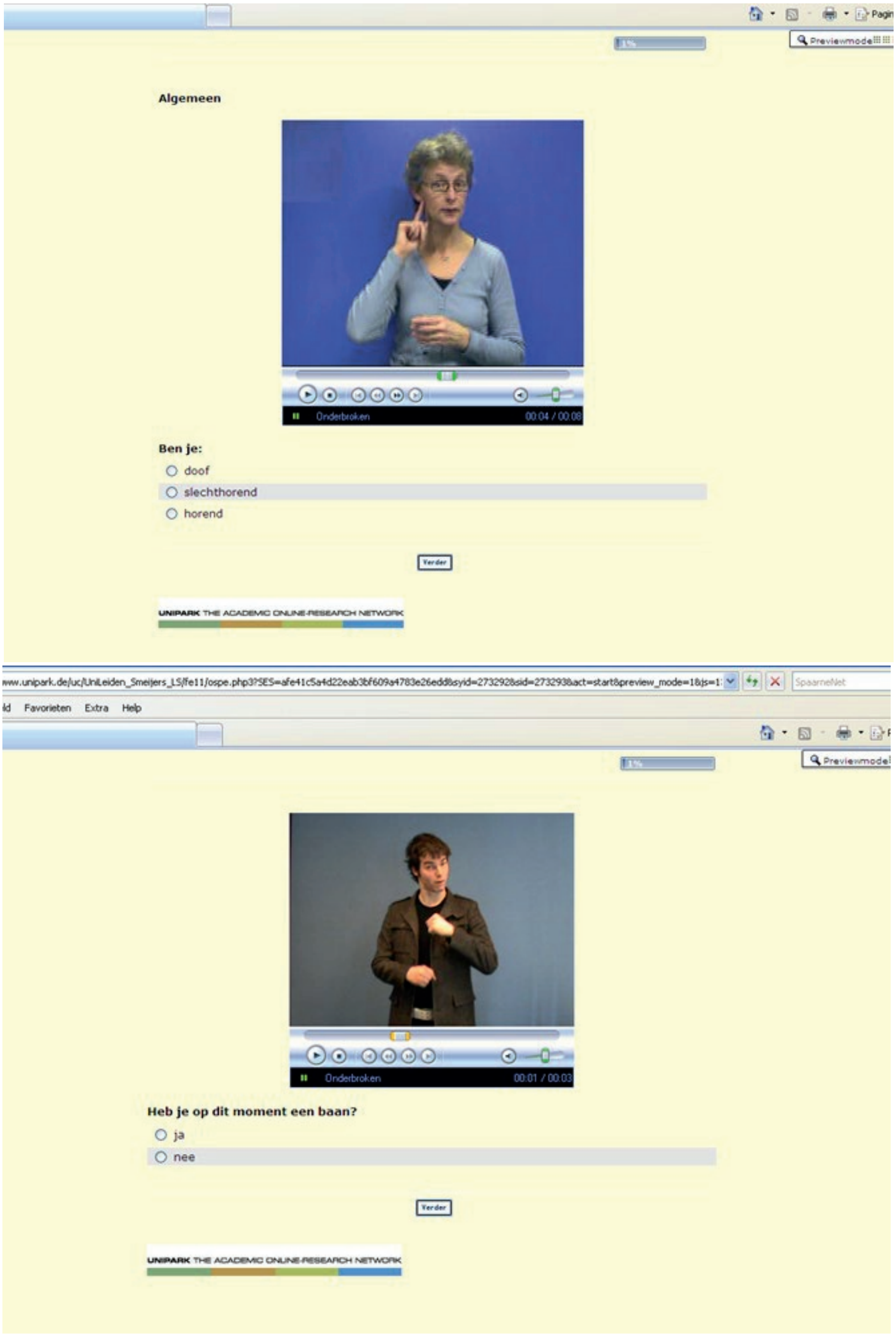
Other researchers have tried to compensate for the difficulty of displaying sign language answers by making the answer options more visual in written text (Graybill et al, 2010; Hocker, 2010; Munro & Rodwell, 2009). (e.g., color coding [green for a positive answer, red for a negative one], the use of illustrations such as thumbs up, flat hand, thumbs down for good, moderate, poor respectively], or smiley faces). However, because colors or illustrations might impart a positive or negative connotation to the answers and thereby possibly add a bias, we decided not to use these.

Some computer-based tests require an answer to every question before the respondent can proceed to the next question. We used this restriction only for the most crucial questions (e.g., "date of birth"). We gave the participants the option of skipping questions because written questionnaires also have the option of leaving a blank in case the test participant does not understand the question or does not know the answer or does not want to answer the question. Filling out an answer just to be able to continue the test would compromise the reliability. Although it was possible to do so, none of our respondents left blanks while filling out the questionnaires.

Testing the questionnaires

Pretesting can be done by many different methods. For the questionnaires we used a cognitive interviewing method based on paraphrasing as a variant of the think-aloud method (KIDSCREEN Group Europe, 2006) (asking the respondents to repeat the item in their own words immediately after answering the item). This technique permits the researcher to find out whether a respondent understands the question and interprets it in the manner intended. It may also reveal weak wordings of items.

Additionally, using the general probing method (KIDSCREEN Group Europe, 2006), the participants were asked whether the items were comprehensible and clear and whether they were easy or difficult to answer. During the translation process the review committee (a committee designed to assess the entire forward-backward process in order to provide a Final Forward Translation) noticed a difference in focus of the two forward translation teams. The forward translation team that was producing the Deaf woman sign model was focusing more on comprehensibility and cultural adaptation, whereas the team that was producing the male interpreter model focused more on making the translation as literal as possible. After consultation, the former team was instructed to translate more strictly, and the latter team was instructed to focus more on a conceptual than a literal translation.



Algemeen

Ben je:

○ doof

○ slechthorend

○ horend

Heb je op dit moment een baan?

○ ja

○ nee

Figure 2: Examples of lay out

During the testing phase differences also surfaced. Testers who were deafened early in life preferred the Deaf woman sign model because they felt that the language used in that version was slightly more accessible. Testers deafened at a later age tended to favor the more literal male interpreter model. Six persons were asked to test all 170 items. They considered only one item to be difficult to understand, because there is no proper translation for the concept "leisure activities" in NGT (see example 3). This is because the concept of leisure time seems to be unfamiliar in the Deaf community.

Example 3. (from WHOQoL-BREF)
"To what extent do you have an opportunity for leisure activities?"

Conducting the questionnaire

In contrast to written questionnaires, questionnaires in sign languages cannot be filled out using paper and pencil. Some sort of visual technical support is needed. We placed our questionnaires in an online environment. Participants filled out our questionnaire at home on their own computer. Several meetings at Deaf clubs and a center for elderly deaf persons were organized. People who did not possess enough computer skills to fill out the questionnaire at home could receive help at these meetings. Assistance was given by three members of our team who were trained to provide only technical assistance; none with regard to content was given.

During the first phase of the study the questionnaire was made available at a secure Internet site. After signing a written consent form, participants received a personal login for the questionnaire. During the second phase of the study this was altered because the procedure seemed to hinder both Deaf and hearing people in their study participation. The Dutch Deaf community is a small, close knit community. Some of its members reported to us that they had doubts about the anonymity since they had to write their name on the informed consent-form, while some Deaf community members were team participants. In addition, some of the possible candidates for our hearing control group reported that the written informed consent procedure was too time consuming.

During the second phase of our study we tried to overcome these barriers by placing the questionnaire in a secure environment without login authorization, enabling people to give online consent instead of written consent.

Participant recruitment

We generated much publicity about the project by articles and announcements in patient group newsletters, magazines, national and local newspapers and websites of Deaf clubs and/or organizations for people with hearing impairment. General information about the study was provided at gatherings of the Deaf community, symposia for people with hearing impairment and medical symposia. In addition, participants were recruited through snowball sampling and newsletters of hearing aid manufacturers.

Informed consent was obtained by providing information brochures and consent forms both in written Dutch and NGT. All of the information was customized for people with weak language skills.

A total of 274 deaf and hard of hearing individuals filled out our questionnaires. The audiological characteristics based on self-reports are shown in Figure 3. Twenty-eight percent of our participants described themselves as members of the Deaf community; 19.7% had at least one deaf parent; 15% had a cochlear implant. Of the 76 participants who were deafened at an early age and described themselves member of the Deaf community, 37% filled out one of the sign language versions of the questionnaire: 4% filled out the sign-supported version: 59% chose the written Dutch questionnaire.

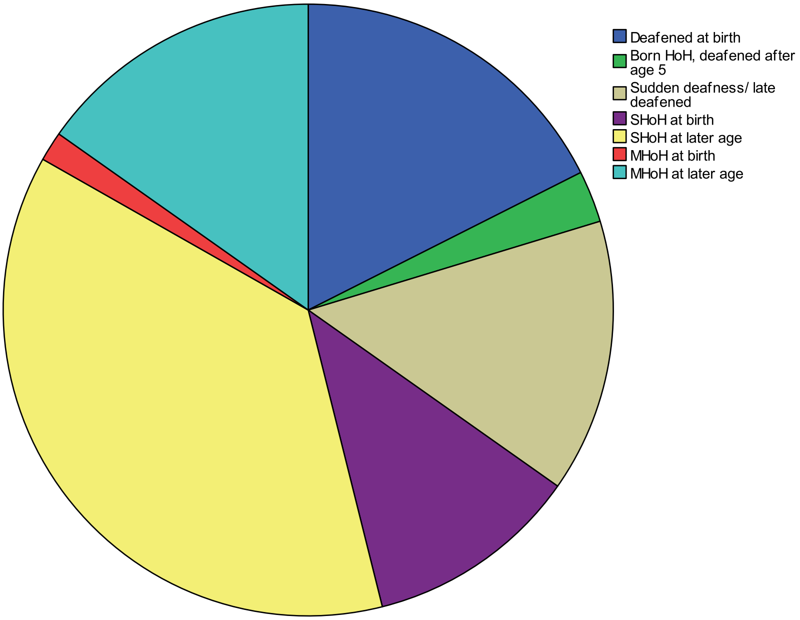


Figure 3: Hearing status of our participants based on self-report (SHOH= severe hard of hearing, MHOH= mild hard of hearing)

Guidelines:

The most important differences between guidelines for spoken language translations and translating for deaf and hard of hearing individuals are the following:

1. Current guidelines always advise translating the original questionnaire using one native speaker of both languages. However, often no native speakers of both the target sign language and the source language are available. Therefore a full forward and backward translation to the written form of the local spoken language (intermediate) has to be made first, in accordance with international guidelines, before starting the forward translation into the sign language of choice.
2. We advise setting up a multidisciplinary team instead of making the translation with one person alone. These teams should include at least the following:
   a) a professionally trained sign language interpreter
   b) a native user of the target sign language, preferably a Deaf communication specialist or Deaf sign language teacher

   If possible, the team should also include the following:
   c) a linguistic specialist in sign language (sign linguist)
   d) a psychologist/ psychotherapist with experience in the development of psychological tests

   All of the team members must be familiar with the target sign language and with the cultures of both the region of the source (written) language and the target (sign) language and have experience with psychological testing.
3. As prescribed in international guidelines, at least two separate translations should be made, differences discussed and adaptations made. International guidelines advise proceeding with one version after performing the first forward and backward translation. The experiences of both translators and translation groups are used to improve what is considered to be the stronger translation. Ideally, when adapting to and translating into a sign language, one should start with four translations (two signed by a sign language interpreter and two by native Deaf signers), choosing the best version of both groups to continue with. Depending on possible local cultural issues more versions might be necessary. Since resources for carrying out this kind of projects are often limited, it will frequently be unfeasible to start with four or more translations. In this context we advise performing two translations using the experiences of the two translation groups to improve both versions. Continuing with at least two versions also serves to minimize the interviewer bias. At least one of the versions should be signed by a Deaf native signer of the target sign language. Other personal characteristics, depending on local culture, should be taken into account.

Conclusions

Specialized mental healthcare for deaf and hard of hearing clients has emerged during the last 50 years in many Western countries. The deaf and hard of hearing client group poses additional linguistic and social challenges to (mental) healthcare providers. This makes the process of diagnosing and treating deaf and hard of hearing clients more challenging than that for hearing clients. Various diagnostic tests have been used for these clients over the years. However, these tests were not specifically developed for this group or were translated only ad hoc. The reliability of such testing is questionable.

We advise the use of internationally validated written questionnaires in this population. However, questionnaires have to be carefully selected, translated, and modified both linguistically and culturally. If this is not properly done, bias can occur, potentially resulting in the misdiagnoses of many clients. With this chapter we hope to raise the awareness of this group's special needs, and we propose a set of guidelines for practitioners and researchers who would like to use standardized tests for deaf and hard of hearing sign language users.

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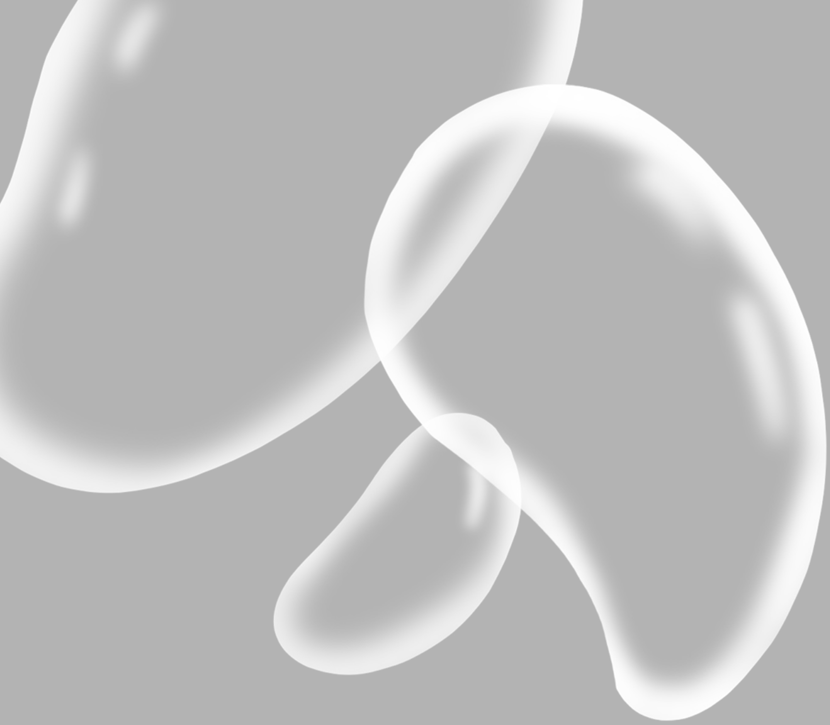
4

The nature and impact of barriers in accessing healthcare



4.1

Towards a treatment for treatment
On the communication between general practitioners and their Deaf patients

Published article:

Smeijers AS, Pfau R. Towards a treatment for treatment: On communication between general practitioners and their Deaf patients.The Sign Language Translator and Interpreter. 2009 Apr;3(1):1-14.

Abstract

This study investigates the nature and extent of communication problems between hearing physicians and their deaf or hard of hearing patients. Thirty-two deaf and hard of hearing patients and their general practitioners were asked to fill in questionnaires regarding communication during the consultations. The authors were interested in (i) the physicians' evaluation of their ability to explain the diagnosis and treatment to the patient; (ii) the patients' evaluation of the degree to which they understand the information supplied by the physician; and (iii) the rating given by the physicians and patients regarding the quality of communication. They were also interested in factors that might influence the communication. In this context, the authors discuss linguistic and cultural issues and address the role of interpreting services. The results indicate that there are worrying problems in the communication between (general) practitioners and their deaf and hard of hearing patients. The nature of these communication problems is comparable to those previously described for the interaction between general practitioners and patients from an ethnic minority group.

Introduction

In the Netherlands, approximately one person in a thousand is born deaf or severely hard of hearing. There is no information available concerning the number of people who become deaf or hard of hearing at a young age. Generally, people who are born deaf or those who are deafened at a young age face serious problems acquiring a spoken or written language. For them, Sign Language of the Netherlands (*Nederlandse Gebarentaal*, NGT) is a good alternative. Just like other signed languages, NGT is a natural language with complex grammatical structures which allows the signer to access information in a natural way and to express opinions, desires, and abstract thoughts. NGT originated around 1790 as a natural language (Schermer *et al.* 1991). Usually, the social life of people who are deaf is mainly situated inside the Deaf community; they attend a school for the deaf, use NGT as a first language, participate in Deaf clubs, have Deaf friends and often have Deaf partners.

Over the past twenty years, there have been discussions of whether or not deaf people have more in common than just their medical condition (i.e. their hearing status) and the fact that most of them use a signed language. Researchers from Great Britain (Ladd 2003) and the United States (Padden and Humphries 1988, 2005) have convincingly argued for the existence of a Deaf culture in these countries. These studies have shown that the Deaf community constitutes a social and linguistic minority within the major 'hearing' culture. This cultural minority is characterized by shared experiences, values, traditions, behavioural rules and, most importantly, the use of a signed language as main mode of communication. Applying these defining characteristics to the situation in the Netherlands, it appears that in the Netherlands, too, such a Deaf (sub-) culture exists. (In order to distinguish between the clinical meaning of the term *deaf* and the cultural meaning of *Deaf*, we adopt the convention of referring to the latter with a capital *D*. It should be noted, however, that below, when referring to the patient group, we use a lower case 'd' (i.e.'deaf') because the group participating in this study was not homogenous with respect to membership of the Deaf community.)

Recent studies on issues in doctor-patient relationships have demonstrated that both ethnic/cultural and language differences complicate the establishment of a satisfying and effective doctor-patient relationship (e.g. Van Wieringen et al. 2002; Schouten & Meeuwesen 2006). Although such ethnic/cultural and language differences are also expected to play a role in the interaction between Deaf patients and their hearing physicians, to date no study has investigated this issue. Hence, the main goal of the present study is to investigate to what extent physicians and their deaf or hard of hearing patients experience communication problems. Clearly, in doctor-patient interaction, the effective and unambiguous exchange of information is particularly important and misunderstandings may have dramatic consequences. It is therefore important to identify potential obstacles and to make efforts to avoid them.

Methodology

For this study, the research code developed at the Amsterdam Medical Centre (AMC) in 2001 was adopted. This research code defines the most relevant types of scientific misconduct (e.g. invasion of privacy) and also includes a guideline for desirable behaviour, that is, how to act scientifically with care and integrity (AMC Research Code Committee 2004; also see Vermeulen 2002).

Data was obtained by means of a questionnaire that was filled in by both the deaf/hard of hearing patient and their general practitioner (GP). Possible participants were enlisted through internet forums and by means of snowball sampling; that is, that deaf and hard of hearing contacts of researchers were asked to forward the inquiry to others who might be interested in participating in the study. Inclusion criteria for the participants were that they were (i) deaf or hard of hearing, (ii) above eighteen years, (iii) lived in the Netherlands, and (iv) gave informed consent following an explanation about the methodology and goal of the study.

The questionnaire contained questions about gender and date of birth. In addition, the patients were asked for their level of education and their profession, whether or not they considered themselves a member of the Deaf community, and for the frequency of visits to their GP (see Table 1 for results).

Both the GPs and the patients were to indicate the mode of communication (primary language) of the patient. GPs were asked whether consultations with their deaf patients were usually more time-consuming than those with their hearing patients. They were also required to indicate whether they were aware of the existence of a Deaf culture and whether or not they thought it was relevant for them to know about Deaf culture. To determine the overall quality of communication, both patients and GPs were asked to evaluate the following three aspects: first, their overall impression of the quality of communication; second, the extent to which the diagnosis could be explained by the GP in combination with their impression of how well it was understood by the patient; and third, the extent to which the proposed therapy could be explained by the GP and was understood. Clearly, providing a diagnosis and proposing a therapy are the main goals of a consultation with a GP. All three questions could be answered across a four point scale: poor, moderate, reasonable, and good. For the patients, the result of the first of these questions, regarding the quality of communication with their GP, is also provided in Table 1.

Table 1: Reported patient characteristics (N = 31).

Gender	Male	29%
	Female	71%
Age	20-40 years	29%
	40-50 years	42%
	50+ years	29%
Level of education	Primary school / lower occupational schooling (LBO)	48%
	Average occupational schooling (MBO)	19%
	Higher occupational schooling (HBO) or university degree (WO)	32%
Primary language	Spoken Dutch	45,2%
	Sign Language of the Netherlands	22.6%
	Both / Signed Dutch	22.6%
Considers him/herself a member of the Deaf community	Yes	84%
	No	13%
Perception doctor- patient communication	Good	26%
	Reasonable	35%
	Moderate	35%
	Poor	3%

As for the evaluative questions, the answers to all three questions were considered equally important in determining the overall quality of communication. In the first two rows of Table 2, the evaluation of the patients and doctors, respectively, are given. In a second step, the answers of patients and their respective GPs were combined in order to establish the amount of overlap between their answers and to get a clearer picture of the perceived quality of communication. Here, the answers of the GP and their patient/s were considered equally important (third row in Table 2).

Table 2: Evaluation of the communication based on the three main doctor and patient questions.

	Good	Reasonable	Moderate	Poor
Evaluation of doctor-patient communication from patient perspective	26%	35%	35%	3%
Evaluation of doctor-patient communication from doctor perspective	22%	74%	4%	0%
Evaluation of reported communication based on both doctor and patient evaluation	13%	48%	39%	0%

Results

A total of thirty-one of thirty-two possible patients who had been contacted returned completed questionnaires. A total of twenty-nine GPs agreed to participate in this study. One GP was on maternity leave and one GP had general issues with participating in studies. For unknown reasons, only twenty-five of the twenty-nine GPs returned the questionnaire. Unfortunately, two questionnaires returned by the GPs had to be excluded because they were not filled in properly. For the analysis of patient characteristics, all thirty-one patient questionnaires were included (see Table 1). However, the eight patients for whom no corresponding GP questionnaire was obtained had to be excluded when correspondence between GP and patient was analyzed.

In this section, we wish to focus on three crucial aspects of the questionnaire. First, we present the results concerning primary language of the patient and awareness of Deaf culture on the part of the GP. Secondly, we report on the evaluation concerning the quality of communication. Finally, we comment on the use of interpreters in patient-doctor interaction, following from patient comments.

Language use and Deaf culture

The patients who participated constitute a varied group consisting of twenty-two female and nine male participants with an average age of forty-seven years (range 29-75 years), with different levels of education, and from various regions of the country. Twenty-five of the participants (81%) consider themselves to be a member of the Deaf community. Fourteen participants (45.2%) indicate that they have Sign Language of the Netherlands as their first language (see Table 1).

With respect to the question concerning the primary language of their patient, 34% of the GPs responses matched that of their patients (see Table 3). Interestingly, 30% of the GPs considered spoken Dutch to be the first language of their deaf patient, while the patients reported their first language as Sign Language of the Netherlands. Clearly, correct evaluation of this particular patient characteristic is a prerequisite for adjusting the delivery of information given to the patient. Treating a native signer, who may not be fluent in spoken Dutch, as if they were a native speaker of Dutch may cause serious communication problems. In addition, only some of the GPs correctly evaluated the level of education of their patient. The significance of this finding is less clear as no comparative figures are available concerning GPs evaluation of the level of education of their hearing patients. Hence, no comparison is possible. In general, it is assumed that GPs are very capable of correctly evaluating the educational level of their patients as this knowledge is necessary to guide the GP's adjustment of information given to the patient, both quantitatively and qualitatively. Incorrect evaluation of this patient characteristic may also be an obstacle for successful communication.

Only one GP was aware of the existence of a Deaf culture and NGT. Some 83% of the GPs, however, consider it relevant to have some knowledge of Deaf culture. One of the deaf participants is a teacher of Deaf culture. Despite this, her GP did not know about the existence of a Deaf culture, nor did he know that NGT is the mother tongue of his patient (see Section 3.2 for discussion of linguistic and cultural issues).

Table 3: Degree of agreement between doctor and patient.

Primary language	Spoken Dutch (21%)	NGT (13%)	Both/Signed Dutch (0%)
Education	Primary school/ lower occupational schooling (LBO) (17%)	Average occupational schooling (MBO) (0%)	Higher occupational schooling (HBO) or university degree (WO) (22%)

Quality of communication

Both the patient and the GP questionnaires contained three questions concerning the quality of communication between the patient and their GP. From the answers to these questions, we can say that the GPs evaluated the quality of communication more positively than their patients (see Table 2). Still, there were no significant differences between individual GPs and their respective patients. When we combine the results for both the GP and the patient questionnaires, communication was evaluated as being either 'reasonable' or 'good' in 61% of the doctor-patient relationships. In the remaining 39%, the communication was evaluated as being of only 'moderate' quality (Table 2).

According to approximately half of the patients, their GPs give 'reasonable' or 'good' explanations. More than half of the patients state that their GPs were often or always able to explain the diagnosis clearly. Also, more than half of the patients have the impression that their GPs are often or always able to explain how their medical problem could be solved.

Interestingly, 91% of the GPs think that they are often or always able to explain the diagnosis clearly to their patients. 30% think they are always able to explain the treatment to the patients in a clear way. 65% think they often succeed in clearly explaining the treatment while 4% feel they only succeed sometimes.

None of the GPs indicate that they find it harder to understand a medical problem presented by a deaf patient than one presented by one of their hearing patients. Still, only 35% claim to always understand the patient's reason for visiting. 57% of the GPs indicate that they often understand the reason. 4% did not answer this question.

With respect to smooth communication, many of the patients used the space for remarks on the questionnaire to indicate that they experienced problems contacting their GP because the primary means of making contact is by telephone.

Use of interpreters

One of the questions we asked the deaf patients was whether or not they booked a professional interpreter when visiting their GP. We note that in the Netherlands, it is usually the deaf patient's responsibility to book an interpreter, and not the responsibility of the medical institution, as in some other European countries. The GPs were also asked whether they sometimes communicated with their patients through an interpreter. 74% of the patients indicate that they never bring an interpreter when visiting their GP. 19% replied that they were sometimes accompanied by an interpreter. Only one of the thirty-one patients always brings a professional interpreter to appointments with his GP. This patient also reports that his GP experiences the presence of an interpreter as positive because it facilitates the communication considerably. The other patients report that they are sometimes accompanied by a relative who functions as an interpreter. One patient stated that she occasionally brings her husband as an interpreter. He is severely hard of hearing, but she reports that his speech is more intelligible than her own. The main reason for not bringing a professional interpreter is that the appointment with their GP takes place on the same day on which it is made, and as a result, professional interpreters are not usually available at such short notice. Others consider it superfluous to bring an interpreter for an appointment which usually only takes a couple of minutes (see Section 3.3).

Remarkably, most of the GPs state that they often use a professional interpreter when communicating with their deaf patients. It turns out, however, that they were referring to the usage of 'Teleplus', a relay telephone service which allows for mediated communication between a regular telephone and a text phone via an operator. Obviously, this is not the same as using a signed language interpreter. Considering the fact that there is no interpreter present at most of the consultations, one would expect that a consultation with a deaf patient is more complicated and therefore more time consuming than with a hearing patient. This expectation, however, is not confirmed by the results (see Section 3.1 for further discussion).

Discussion

Communicating with a deaf patient

The information compiled by means of the questionnaires indicates that communication problems are experienced in more than one third (39%) of the contacts between a deaf patient and their GP. Yet the GP's responses demonstrate that most are not even aware of the existence of these communication problems.

35% of the GPs claim that the reason for the deaf patient's visit is always clear to them while 57% state that the reason for the visit is often clear. This can be interpreted in two ways. The positive interpretation of these responses is that there are no GPs who would point out that they often do not understand exactly the reason for their patient's visit. On the other hand, however, it is certainly worrying that in more than half of the contacts, the GP does not always understand the exact question of their deaf patient. Obviously, a good understanding of the patient's problem is a prerequisite for a consultation which is satisfying for both the patient and the GP and which yields the desired results. One of the commonly reported irritating issues for deaf patients is the use of terms like *doofstom* ('deaf and dumb'), which seems to arise because of a lack of knowledge of the part of the GPs about deafness, signed languages, and Deaf culture. In this context, it is a positive sign that almost all of the GPs in this study state that more knowledge about Deaf culture could be relevant to their practise.

Remarkably, according to 26% of the GPs, a consultation with a deaf patient is never more time consuming than one with a hearing patient. 61% of the GPs report that this was sometimes the case while 13% report that consultations with deaf patients often take more time. In order to understand these impressions, it is important to know that GPs in the Netherlands have an average of seven minutes per patient consultation. Clearly, this is a tight time schedule. Hence, one would expect that given a more complex communication situation (in the absence of an interpreter), a consultation should always take longer. It seems likely that the limited amount of time available for the consultation is responsible for the problems deaf patients experience in understanding the explanation of diagnosis and proposed treatment. The allotted time slot is equal to that for hearing patients. Due to communication problems, however, less information can be exchanged within this time frame. Possible ways to overcome these challenges to communication, such as lipreading and writing messages, are time-consuming and tend to be impeded by a lack of clarity on both the doctor's and the patient's part.

An important outcome is that in 39% of cases, the communication between 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 originating from an ethnic minority group. Van Wieringen et al. (2002) 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.

A clear shortcoming of our explorative study is that there was no hearing control group. Given this, we cannot say in any categorical sense whether deaf patients experience significantly more communication problems than hearing patients when consulting their GPs. However, the composition of the group of patients participating in the present study seems to be representative of that of the Dutch Deaf community and similar in nature to those of Van Wieringen et al. (2002), who demonstrated that both ethnic/cultural and language differences complicate the establishment of a satisfying and effective doctor-patient relationship. We therefore assume that it is quite likely that deaf and hard of hearing patients, just like patients from ethnic minority groups, face more problems in the communication with their GP than patients from the same cultural group as the GP. We acknowledge the need to complement the present study with a survey of hearing Dutch patients that makes use of exactly the same research protocol.

Linguistic and cultural issues

It is difficult to determine which factors are responsible for these communication problems. It appears that most GPs are not aware of the fact that Sign Language of the Netherlands is a natural, fully-fledged language that allows the Deaf person to communicate in an efficient and effortless way. In addition, they are unaware of the fact that most people who are born deaf or are deafened at a young age have NGT as their native language. Even if GPs know that their patient was born deaf, they tend to expect that the patient understands spoken Dutch as if it is their native language. This misunderstanding can result in communication problems. Obviously, a physician who is not aware of the fact that the addressee has a different native language will make little effort to adapt their communication to the needs of the patient. Moreover, most GPs seem simply to assume that deaf patients have no problems understanding written information. Frequently, however, this is not the case. In particular, elderly deaf people who were deafened at a young age, did not always have the chance to learn to read and write properly – a problem resulting from educational policy in the past. The strictly oral educational system that has been employed at deaf schools in the Netherlands for many years made it difficult for deaf children to acquire written language (Wauters 2005). But even for those Deaf people, who have learned to read and write, one still has to keep in mind that their native language is often NGT and not spoken or written Dutch. General trends internationally suggest that the average reading age for averagely intelligent deaf people across the European Union is 8.5 to 9 years (Leeson 2006).

Given these limitations, it is clear that in general, technical and abstract information and in particular, complicated medical information, can easily be misunderstood. Therefore, information supplied in written form should be adapted by using short sentences and unambiguous words and by avoiding complex word structures and infrequent words or medical jargon. Typing information on the GP's computer is a communication strategy that is often used. While this may be helpful to some extent, it is not always an optimal way to communicate, given the problems with written information described above. Hence, writing down information or instructions does not necessarily guarantee that the deaf patient has understood this information or instructions and can give a delusive feeling of security to the GP.

The main focus of this study has been on the self-reporting of communication problems caused by linguistic factors, that is, the lack of a communication mode that is fully accessible to the Deaf patient. However, another factor that may contribute to the communication problems is that generally, GPs are not aware of the existence of a Deaf culture and, as a consequence, of possible cultural differences. The questionnaire was not specific enough to find out whether the attested communication problems are (at least partly) caused by such cultural differences. Although, to the best of our knowledge, to date no research has been done on the influence of Deaf culture on medical care-giving, it is known that GP-patient dyads sharing different cultural backgrounds may have a negative influence on communication (Schouten and Meeuwesen 2006). When a GP is aware of the fact that the patient comes from a different cultural background, they can take this into account in order to reduce potential communication problems. Research shows that just two of the eight Dutch medical faculties offer courses that address the issue of cultural diversity. The remaining six only briefly tackle this topic in the context of other subjects. However, to date no Dutch medical educational program trains their students with regard to dealing with Deaf patients.

Professional and non-professional interpreters

This study also shows that most deaf people in the Netherlands do not bring an interpreter with them when they visit their GP. When they do take an interpreter with them, they usually take a relative, not a professional interpreter. The main reason for this is that it is difficult to find an interpreter on short notice. Moreover, many deaf people consider it a waste to hire an interpreter for a consultation which usually only takes a couple of minutes. This is motivated by the fact that Deaf people in the Netherlands have access to a limited amount of interpreter hours available per year, which are paid for by the government. Nor is Sign Language of the Netherlands recognized as an official language, and consequently, only limited facilities in NGT are currently available.

Based on a review of the literature, Flores (2005) concludes that the quality of medical care is seriously reduced when no professional interpreter is used for American patients who do not speak English (see also Angelelli 2004). Not only do these patients participate less in preventive screening programs, they also undergo more medical tests, resulting in higher medical costs. These patients often state that they do not understand the diagnosis and proposed treatment very well and that they would have liked their physician to provide more detailed information. According to Flores, these problems also occur when non-professional interpreters, such as relatives, are used. Some studies show that untrained (family) interpreters leave out or misinterpret up to half of the questions asked by the physician. Consequently, there is a higher risk of medical mistakes with potentially serious clinical consequences within this patient group. Moreover, negative side effects of drugs are often not translated and sensitive or embarrassing problems are more likely to be avoided than in a situation in which a professional interpreter is present.

The present study has shown that deaf patients would like to get more information and clarification about the diagnosis and the proposed treatment from their GP. At first sight, using an interpreter to accomplish this task appears to entail additional medical costs. Flores (2005), however, has shown that in the absence of a professional interpreter, medical costs may also increase due to additional medical testing. It would certainly be interesting to conduct a cost-benefit study for the usage of signed language interpreters and *schrijftolken* (speech-to-text reporters) in medical settings in the Netherlands. In this context, it would also be interesting to know to what extent GPs and patients evaluate professionally interpreted consultations differently from non-interpreted ones. It is expected, that the presence of a professional interpreter will improve the quality of communication and reduce misunderstandings.

Many deaf and hard of hearing patients indicated that they face problems when trying to reach their GP. In many cases, it is not possible to use email for services that are available by telephone for hearing patients, such as, making an appointment, asking a short question, or ordering a repeat prescription. As a consequence, deaf patients have to visit the practice for all of this, despite the fact that establishing an alternative email service would be technically simple. In acute situations, the lack of such a service can have dangerous consequences. Medical practices usually do not have a fax, email, or other electronic device to receive instant messages other than the telephone. Teleplus, a telephone relay service, often has long waiting times and sometimes this service is not available at all. Given this, it may be almost impossible for a deaf person to reach the medical services in a medical emergency without the help of a hearing person. A possible solution for this serious problem might be a special e-mail address for use by deaf patients, which activates a pop-up on the computer screen of the medical nurse when it comes in. Such a technically simple device could help avoid potentially dangerous situations.

Note that one goal of the present study was to evaluate the benefit of bringing a professional interpreter to consultations. However, given that – much to our surprise – only one of the participating patients regularly brought an interpreter to appointments with their GP, this aspect could not be evaluated. Also, as noted in Section 2.2, a fair number of GPs confused the use of a professional sign language interpreter and the use of Teleplus. Hence, their answers to the questions about interpreting are not informative and illustrate the lack of knowledge about use of sign language interpreters.

The questionnaire did not address the question whether a patient had ever changed their GP because of communication problems. Assuming that patients would not stay with their GP if they were dissatisfied with the level of communication available, we must take into account that the results presented here are possibly more positive than if communication with all GPs had been considered. Therefore, broader and more detailed research on communication problems and their consequences is called for. The training of physicians in communicating with deaf and hard of hearing patients has to be improved and the inclusion of information on topics such as signed languages and Deaf culture is desirable. Official recognition of Sign Language of the Netherlands would have a positive effect on the social acceptance of NGT. As a positive side effect, official recognition would facilitate the increased provision of professional interpreting services, thereby improving the communication between Deaf patients and their GPs. We have to bear in mind, however, that it is not guaranteed that interpretation between Dutch and NGT will solve all communication problems.

Conclusions

The results of this study indicate that deaf and hard of hearing patients experience considerable communication problems in interacting with their GPs. The extent and nature of these problems appear to be comparable to the problems that have been described for the communication between patients from an ethnic minority group and their GPs. For a successful consultation to be possible, it is absolutely essential that physicians become more aware of the different linguistic and cultural background of their Deaf patients, so that they can take this into account during the consultation. At present, we have to draw the sad conclusion that most physicians are not aware of these factors. More education on communicating with deaf and hard of hearing patients and more information on Deaf culture and the Deaf community in general is therefore required. The official recognition of Sign Language of the Netherlands would also potentially help to improve the situation. Hopefully, this study will be a first step towards improvements. A list with guidelines for physicians, providing guidance about how to avoid the most common communication problems is supplied in Table 4.

Table 4: *Points of attention* for physicians when communicating with Deaf patients.

1. Discuss your communication/ how communication can be improved with your deaf patient.
2. Be aware of possible cultural differences during the consultation.
3. If you write down information for the patient, make sure that this information can be taken home. Use short, explicit, and unambiguous sentences. Avoid complex and infrequent words or medical jargon.
4. At the end of a consult, check whether more information on diagnosis or treatment is necessary.
5. Always reserve double consultation time for deaf and hard of hearing patients to make sure that there is enough time to clarify the reason for the visit and for giving information.
6. Indicate clearly that the patient is deaf on their file so that the practice assistant and possible substitutes are aware of this immediately.
7. Make sure that the practice can be reached by deaf and hard of hearing patients in emergency situations (also at night and on weekends/holidays).
8. Offer the possibility to make appointments and to ask for a repeat prescription by email.
9. Especially in cases where psychological problems are presented (or are likely to do so) always consider using an interpreter.

Clearly, many of the issues tackled in this study require further in-depth research. First of all, the research should be repeated with a hearing Dutch control group. Moreover, it is desirable to know more about the exact causes of the communication problems, in particular, the influence of cultural and language differences. Questionnaire design for this study did not allow for testing the impact of cultural differences. Clearly, this is a topic that would need to be addressed in any follow-up study. As far as the language differences are concerned, the role of interpreted GP interactions certainly deserves further study. It is expected that the use of interpreters may help in reducing and ameliorating the communication problems caused by language barriers. Possible benefits include increased confidence on the side of the patient, maximisation of information transfer, and enhanced use of the allotted time. It has to be pointed out, however, that empirically, it is not clear at present what the exact benefits of professional (or non-professional) signed interpreting in medical consultations are.

Acknowledgments

We are indebted to the patients and GPs who agreed to participate in this study. Moreover, we wish to thank Joke A. Haafkens from the Academic Medical Center, Amsterdam, for her advice during this study as well as Lorraine Leeson and an anonymous reviewer for invaluable comments that helped improve the paper.

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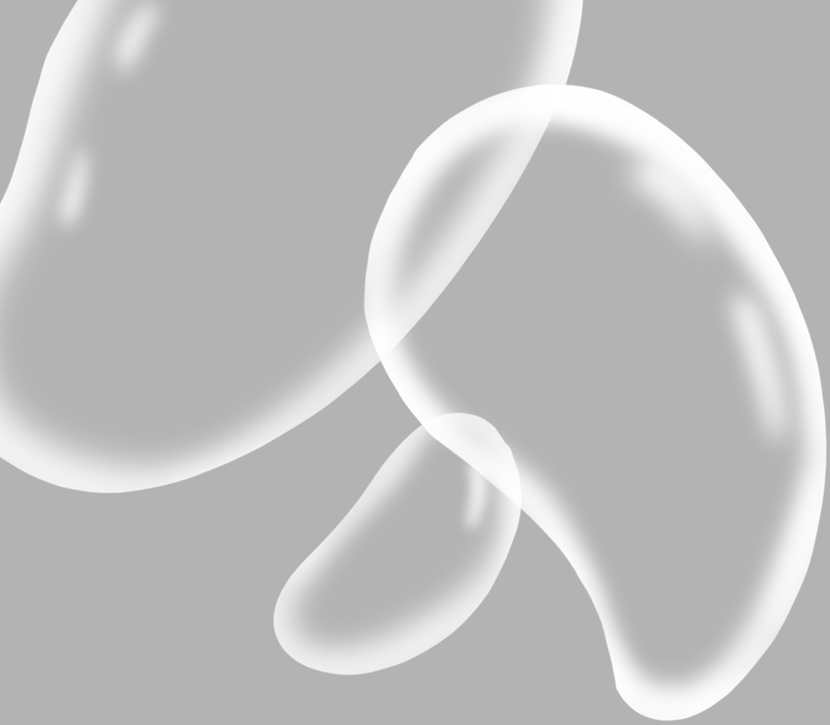

4.2

Health related quality of life of people who are deaf or hard of hearing

Published article:

Smeijers AS, Ens-Dokkum MH, van den Bogaerde B, Oudesluys-Murphy AM. Health related quality of life of people who are deaf or hard of hearing. Journal of Special Education and Rehabilitation. 2018:19(3-4);51-68

Abstract

Purpose: Patient groups and healthcare workers report that people who are deaf or hard of hearing (DHH), have poorer health and wellbeing. The aim of this study is to gain insight into the health of DHH people in the Netherlands.

Methods: The physical and mental health of participants was measured using the World Health Organization Quality of Life- Bref scale (WHOQoL-BREF). Participants filled out an epidemiological questionnaire and questions about the mode of language they generally use. All questionnaires were translated into two versions of Sign Language of the Netherlands (NGT) according to a forward-backward translation protocol, a written version and a sign supported Dutch (SSD) version of the questionnaire were also provided.

Results: The questionnaires were completed by 274 DHH people. Both deaf and hard of hearing people, regardless of the age of onset, reported having poorer physical health than their hearing peers. Hard of hearing people reported more psychological difficulties than control group.

Conclusions: It is important that DHH people are recognized as a patient group with specific health problems. More research into the nature and effects of this specific health problems is needed. The creation of more awareness of these health problems among DHH people and their healthcare workers is essential.

Introduction

Healthcare workers and patient groups widely report that people who are deaf or hard of hearing (DHH) have a poorer health related quality of life than hearing people. The reason they most often put forward is that DHH people experience barriers in accessing healthcare, with substantial consequences for their health and wellbeing. Several authors have described barriers that may have a negative impact on the health of DHH people (1-4). These barriers may vary, depending on residual hearing, the age of onset of the hearing loss and the degree to which the individual accepts and uses available support such as amplification, sign language interpreters or speech to text interpreters. Possible barriers that have been described so far in the literature are:

Barriers due to reduced medical knowledge

Among hearing people much health information is circulated during informal conversations and from overhearing these exchanges (implicit learning). DHH people do not have access to this type of ambient information and therefore miss out on much knowledge (5-8). As for explicit learning, e.g. in education, most children with severe DHH used to have only limited exposure to health information in schools (9), because there is often a predominant focus on language development and practical language skills, at the cost of subjects such as biology.

People who function severe DHH from an early age often develop low language and literacy skills (10-12). Literacy skills are low because when sounds of a language (phonemes) cannot be heard, there is no logical correlation between a given concept and its written form (letters/characters). The only option is to memorize which combinations of letters are used and in which order, to describe this concept. These people also cannot use vocalization when reading either. This means that only those words that they have previously read and of which they have memorized the character construction can be read fluently. This contributes to the limited knowledge often experienced in DHH.

Communication barriers

Even a highly skilled lip-reader is able to ‘read’ only 20-40% of what is said (13). This suffices to follow a fairly predictable conversation in common everyday circumstances. However, during a medical consultation, when many unknown terms are used and the patient may be stressed, this method often proves to be inadequate (10, 12). The use of speech-to-text interpreters and/or sign language interpreters in medical settings may help overcome these barriers. These supports are not always routinely used and the amount of information transferred from the physician to the patient and vice versa is therefore restricted (14). Communication barriers may also pose logistic problems; for instance to make an appointment or ask for a repeat prescription it is often necessary to contact the physician's office by telephone or go there in person.

Deaf cultural barriers

People who are deaf or hard of hearing from a young age have many characteristics in common (15, 16). Due to limited access to spoken language and limited acceptance of sign language worldwide, they tend to form a cultural-linguistic minority group within the hearing population which is referred to as the 'Deaf community'. This community has its own norms and values which may compromise healthcare access in the same manner as cultural and language barriers influence healthcare access of ethnic minority groups (14).

Attempts are being made to create awareness of these barriers among healthcare providers. Advice for health workers includes booking a longer consultation time, exploring the optimal mode of communication with the patient and hiring interpreters. It extends to creating specialized facilities and using special information and communication technology (ICT) programs to support communication and education (1).

The aim of this study is to gain insight into the state of health of DHH people in the Netherlands. For this purpose we performed a large study to generate quantitative data about the physical and mental health of DHH individuals. In this paper the term deaf or hard of hearing (DHH) is used for anyone with a hearing loss. The term hard of hearing (HoH) is used for people with a hearing loss who have enough residual hearing to understand some spoken language. The term deaf is used for people without sufficient functional hearing to perceive spoken language. People within this group who have been deaf from a very young age, use a sign language as their first language and who identify themselves as members of the Deaf community are described as Deaf with a capital D. When we refer to the audiological feature deaf, deaf is written with a small d.

Netherlands

On June the 14th 2016 the Dutch government signed the United Nations convention on the rights of persons with disabilities. This is the first legislation in the Netherlands which specifically addresses the rights of DHH people. At the time of this study DHH people had no legislative rights yet concerning specialized facilities other than those based on the principal of equal rights.

There is an extensive network of mental health facilities for DHH people in the Netherlands. In other areas of the Dutch healthcare system facilities for DHH are restricted. Sign language of the Netherlands (NGT) is not recognized as an official language, public information is not translated into NGT and within the healthcare system and society in general, speech-to-text interpreters and NGT interpreters are rarely used in medical situations (17).

Methodology

Here we report on a quantitative assessment of health related quality of life of DHH persons in the Netherlands.

Study group

In this study, which is a part of a larger project, inhabitants of the Netherlands who are DHH and older than 18 years were eligible for entry. The definition "DHH" was based on several self-reported items of hearing functioning. The study was designed to avoid inclusion of people with mental or cognitive issues.

Control group

For comparison with the general population in the Netherlands we used data from the Dutch World Health Organization Quality of Life- Bref scale (WHOQoL-BREF) database (18). Persons were matched for age, sex and level of education.

Participant recruitment

Publicity around the project was generated by articles and announcements on websites, newsletters of patient groups, magazines, national and local newspapers and websites of Deaf clubs and/or organizations for/of DHH people. General information about the study was provided at gatherings of the Deaf community, symposia for DHH people and at medical conferences. In addition, participants were recruited through snowball sampling and newsletters produced by manufacturers of hearing aids.

Participants filled out questionnaires at home on their own computer. People who did not possess enough computer skills to fill out the questionnaire at home could receive assistance at special meetings. Assistance was given by three members of the research team who were trained to provide technical assistance only; no assistance was given with regard to the content.

During the first phase of the study the questionnaire was placed within a secure internet environment. After signing a written consent form, participants received a personal log-in for the questionnaire. During the second phase of the study this was altered because the procedure seemed to hinder participation in the study. Therefore the questionnaire was placed in a secure environment without log-in authorization, enabling people to give online consent instead of written consent. Data were checked to prevent duplications.

Questionnaires

Health related quality of life was assessed using the World Health Organization Quality of Life- Bref scale (WHOQoL-BREF). The WHOQoL-BREF is an internationally standardized, methodologically strong questionnaire. It consists of four subdomains, viz. physical, psychological, social and environmental QoL (19). For this article we will focus on results of the first two mentioned subdomains, which we regard as the medical domains.

The participants also filled out an epidemiological questionnaire which included questions about age, sex, audiological status, audiological features of parents, amplification, socio-economic features, level of education, language skills and demographics. Participants were also asked whether or not they used a sign language (SL), i.c. Sign Language of the Netherlands, and to what extent: mainly NGT, mainly sign supported Dutch (SSD), some NGT and/or SSD alternated by Dutch, or Dutch only. This questionnaire may be obtained from the corresponding author.

Preparation of questionnaires

Questionnaires are reliable only when provided in a person's first language. For this reason we translated, adapted and tested all our test material into NGT (20). All questionnaires were translated into two versions of NGT according to a forward-backward translation protocol (20). A written version and a sign supported Dutch (SSD) version of the questionnaire were also provided. We used Unipark software to manage the questionnaires in an online environment (21, 22).

Statistical information

This is the first inventory of this kind in the Netherlands. Apart from two Austrian studies, no further comparable international data are available. We based our power calculations on these two Austrian studies that included members of the Deaf community and hard of hearing participants (2, 3). It was calculated that we needed 54 deaf and 189 hard of hearing participants to obtain a power of 0.8 on the WHOQoL-BREF. Our power calculations, database and statistical analysis plan were checked by a statistician prior to executing the study. To minimize the risk of under-powering our study, inclusion of participants was continued for an extra three months after reaching our calculated power. Analyses were performed in accordance with our analysis plan. The outcomes of the DHH groups were compared to those of the general population control group, matched for age, level of education and sex (18).

SPSS software was used to perform statistical analyses. All analyses were performed independently by two members of the team.

Ethics

The research protocol was assessed by a local scientific committee and the regional Leiden University Medical Centre medical ethical committee prior to the start of this study.

Results

The questionnaires were filled out by 274 DHH people. Audiological characteristics based on self- report are shown in Figure 1. Other characteristics and demographics are shown in Table 1.

The audiological functioning of the analysis group was based on self-report; participants had to answer questions about their own perceived hearing status and functional hearing, including questions such as ability to understand speech in a group conversation, understanding speech in a one to one conversation and the degree of hearing loss in dB.

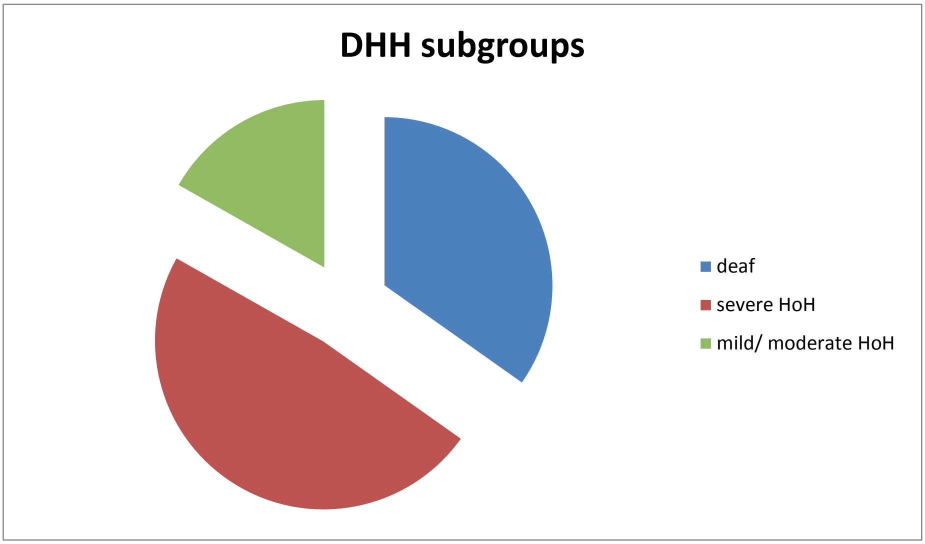

Figure 1: DHH subgroups

We identified seven subcategories on the basis of the age of onset and the amount of the hearing loss as these factors may influence the difficulties and barriers a DHH person may experience (Figure 1). Approximately half of our participants were born DHH or became DHH during childhood or adolescence, 33% of our participants were born DHH or became DHH before the age of five, 20% of the participants became DHH after the age five years but before the age of 21. The other half became DHH at a later age. Less than 5% of our participants were born hard of hearing and became deaf at a later age, or were born mild hard of hearing (MHoH) without significant deterioration during their life.

Table 1: Participant characteristics.

	Deaf	Severe Hard of hearing	Mild Hard of hearing	Control group
Age (derived of year of birth)				Population based control group was matched for age, sex and level of education for all DHH groups separately.
• 18-26	10.1%	4.8%	2.3%	
• 27-36	9.0%	8.9%	2.3%	
• 37- 46	16.9%	12.1%	16.3%	
• 47- 56	17.9%	19.4%	16.3%	
• 57- 66	30.4%	35.4%	30.2%	
• 67- 76	11.2%	16.2%	18.6%	
• 77- 83	4.5%	3.2%	14.0%	
Sex				
• Female	71.7%	71.2%	52.3%	
• Male	25.0%	28.1%	45.5%	
• Unknown	3.3%	0.7%	2.2%	
Level of education				
• Prim./secondary school only	29.9%	13.6%	11.6%	
• Junior secondary technical school	8.9%	9.6%	7.0%	
• Vocational training	26.7%	32.8%	34.9%	
• Bachelor degree	26.7%	34.4%	39.5%	
• Master degree	7.8%	9.6%	7.0%	
Employment	66.7%	53.2%	60.6%	
Having cochlear implant	34.9%	12,2%	2.0%	
Language use				
• Primarily SL	21.8%	0.7%	2,3 %	
• SSD or SSD/SL and spoken language	47.8%	11.3%	6.8%	
• Spoken language only	30.4%	88.0%	90.9%	

In the Netherlands people retired at age 65 up to 2014. Therefore people born before 1945 were excluded from job percentages. (SL= sign language, SSD= sign supported Dutch)

Compared with the general population control group (18) all DHH participants reported highly significant lower (poorer) scores for physical HR-QoL (Table 2a). The hard of hearing group also reported significantly lower (poorer) scores for psychological HR-QoL (Table 2a). Within the subgroup of people who were severely hard of hearing before the age of five years this difference was not significant (Table 2b). People in both the deaf and hard of hearing groups reported significantly lower (poorer) scores for social wellbeing compared to the general population control group.

The group of deaf people, the group of moderately hard of hearing people (MHoH) and the group of people who became severely hard of hearing (SHoH) after the age of five years reported lower (poorer) scores for environmental wellbeing (Tables 2a+b). The same tendency was found in the group with SHoH before the age of five and the whole SHoH group, but these figures are not significant (Tables 2a+2b).

Significant positive correlations were found between both the physical and the psychological QoL and the use of SSD/NGT: more extensive use of supporting signs/SL was related to higher (better) psychological and physical QoL scores (Table 3). A negative correlation was found between the environmental QoL and the use of SSD/NGT but this relationship was not significant (Table 3).

Table 2a: Means and standard deviations (in brackets) for WHOQOL-BREF domain scores.

WHOQOL-BREF scale	Deaf	P Deaf vs GPop	SHOH
Physical	62.13 (17.58)	0.0413×10^{-12} **	55.84 (18.47)
Psychological	68.18 (13.29)	0.479	62.78 (14.11)
Social	67.78 (19.50)	0.036*	65.71 (19.21)
Environmental	68.28 (14.16)	0.0985×10^{-3}**	71.56 (16.62)

Domain scores range from 0 to 100. Higher scores correspond with higher quality of life. Means and standard deviations in the table are unweighted. P values are weighted for sex, age and education level.

Table 2b: Means and standard deviations (in brackets) for WHOQOL-BREF domain scores.

WHOQOL-BREF scale	Deaf before age 5	P Deaf before age 5vs GPop	SHOH before age 5	P SHOH before age 5 vs GPop
Physical	63.85 (17.28)	0.001*	56.40 (18.07)	0.012×10^{-3}**
Psychological	69.56 (13.61)	0.11	62.94 (13.00)	0.335
Social	69.27 (81.29)	0.56	72.14 (13.15)	0.984
Environmental	68.52 (14.25)	0.002*	73.32 (15.15)	0.200

Domain scores range from 0 to 100. Higher scores correspond with higher quality of life. Means and standard deviations in the table are unweighted. P values are weighted for sex, age and education level.

P SHOH vs GPop	L/MHOH	P MHOH vs GPop
0.0276x10^{-24}**	50.26 (18.00)	2.28x10^{-12}**
0.624x10^{-6}**	59.00 (11.33)	0.285x10^{-6}**
0.2266x10^{-3}**	59.85 (25.10)	0.03*
0.062	69.39 (16.01)	0.04*

The stars in the table indicate the significance of the weighted data compared to hearing controls[19] (*p<0.05, **P<0.001). GPop= General Population control group, SHoH= Severe Hard of Hearing, MHoH= Mild Hard of Hearing

Deaf after age 5	P Deaf after age 5 vs GPop	SHOH after age 5	P SHOH after age 5 vs GPop	L/ MHOH after age 5	P MHOH after age 5 vs GPop
59.62 (17.58)	0,034x 10^{-3}**	56,03 (16,84)	9.064x 10-^{15}**	50,00 (17,05)	1.6708x 10^{-9}**
67.71 (12.38)	0.549	63,40 (11,26)	0.512x 10^{-3}**	59,76 (11,10)	0.077x 10^{-3}**
68.52 (21.56)	0.859	64,67 (18,23)	0.003*	61,18 (22,09)	0.008*
69.23 (13.59)	0.04*	72,28 (14,62)	0.017*	69,57 (15,01)	0.011*

The stars in the table indicate the significance of the weighted data compared to hearing controls[19] (*p<0.05, **P<0.001) GPop= General Population control group, SHoH= Severe Hard of Hearing, MHoH= Mild Hard of Hearing

Table 3: Correlation between WHOQoL-BREF subscales and the use of sign supported Dutch/Sign language of the Netherlands.

	Extent of using supporting signs/sign language	
	P-value	**R^2**
Physical QoL	0.0008**	0.045
Psychological QoL	0.0047**	0.032
Social QoL	0,1400	0.009
Environmental QoL	0.0623	0.014

The table shows the p values and the determination coefficients (R^2) of the correlation between the use of sign supported Dutch/Sign language of the Netherlands and reported quality of life on the WHOQoL-BREF. (*$p<0.05$, **$P<0.001$)

Discussion

Physical health

In this study all three subgroups of DHH people reported significantly lower (poorer) scores for physical wellbeing than the general population control group (Tables 2a+b). This difference was highly significant in the group of people who were DHH from a young age. This outcome is in agreement with other studies (e.g.(2, 3)).

Three possible reasons for the lower scores of people who have been DHH from a young age have been identified. First, barriers to the access of healthcare, as described in the introduction, may have a negative impact on the health of DHH people.

Second, several studies found specific increased health risks among congenital DHH people like increased HIV infection rates, increased prevalence of substance abuse and a higher risk for cardiovascular disease and metabolic syndrome (4, 23-31). Third, it may be a consequence of the fact that they form a special subgroup with respect to the cause of their DHH. Congenital DHH may be the result of genetic or congenital disorders, accompanied by lifelong physical and mental sequelae. The incidence of these disabilities in DHH children is estimated to range from 25-34% (32).

This study is part of a larger research project. The aim of this project is to study the first two possible causes for lower HRQoL-scores in DHH people. Therefore people with congenital DHH and severe additional disabilities were excluded by the design of this study, but some degree of DHH related disabilities cannot completely be excluded.

Although we cannot conclude from this study that barriers to the access of healthcare and group specific healthcare risks are the main cause of the lower physical quality of life of congenital DHH people, it seems clear that they can have a negative influence on their health and should be removed as far as possible.

People who became DHH at a later age may experience barriers to healthcare access as well.

Next to this they may have comorbidities related to the cause of their DHH. The people with comorbidities related to the cause of their DHH were not excluded by design of the study, therefore we cannot make any statements about the impact of the different possible causes for lower physical HRQoL among people who became DHH at a later age.

Psychological health

Scores for psychological health were higher (better) in the deaf subgroups than in the hard of hearing subgroups: In contrast to other studies, deaf participants in the Netherlands did not report more psychological problems than the control group.

We do not think that this is caused by methodological issues such as choice of instrument or participant recruitment. The WHOQoL-BREF was especially chosen because of its ability to reveal internalizing problems because of their higher prevalence in DHH people according to the literature. As some of the meetings we organized were located close to a psychiatric facility for DHH people, and several of their patients participated in this study, we have no reason to believe that psychologically healthy people were overrepresented in our sample.

A possible explanation for the better scores for psychological wellbeing of deaf people than of hard of hearing people may lie in the provision of specific mental healthcare facilities for deaf people in the Netherlands. No research has been done to evaluate the effect of specialized facilities, but it is possible that the extensive availability of these services may have influenced the finding of a better perceived psychological quality of life in deaf people, compared to the hard of hearing participants who have limited access to specialized healthcare facilities.

Another explanation may come from the fact that, until relatively recently, children with mild hearing loss were not diagnosed at a young age. They started school without knowing about their hearing loss and were often wrongly accused of being stupid or unwilling to listen. This may have lowered their self-image and their psychological QoL accordingly.

We found that the psychological health of Deaf people in our study was better than that reported in studies from other countries (3). This may be the result of an extensive network of facilities for mental health support for deaf people in the Netherlands.

The mode of language and Deaf culture on health related quality of life

There are many debates in the literature and in (clinical) practice concerning which subgroups of DHH people can benefit from the use of sign language, and to what amount. We found a significantly positive relationship between physical and psychological health, and the use of sign language and/or supporting signs. It appears that the protective effects of using as many modes of communication as possible is stronger than the possible negative effects of learning a language only partially. We did not find a minimal required ability to use sign language or supporting signs for these positive effects, the effect was present among all DHH subgroups. The relationship was continuous: the more sign (language) a person uses, the higher the score on the QoL scales.

Strengths and limitations

Unintentional selection of participants may influence the outcome of studies. We attempted to minimize this by making the study design as undemanding as possible, and by trying to reach a broad profile of the group we intended to study, e.g. by using newsletters of a hearing aid manufacturer instead of addressing patient groups only. Although there was an overrepresentation of females in our study group (two-thirds of the participants were female), the number of male participants was high enough to perform a reliable statistical correction for sex.

A possible bias in the classification of the DHH group is that all audiological parameters are based on self-report. This method was chosen because full audiological examinations would be expensive and time consuming for the participants, whereas this would probably not provide much additional information on hearing function. By enabling participants to fill out the questionnaires at home in their own time, the threshold for participation was lowered.

With respect to age of onset and degree of hearing loss, the study population seems to be a representative sample of the Dutch DHH even though relatively few people with a mild, non-progressive DHH from birth are included.

Implications for the future

Both deaf and hard of hearing people, regardless of the age of onset, report poorer physical health related quality of life than their hearing peers. More knowledge and awareness is needed concerning the specific health problems of DHH people. It is important that DHH people are recognized as patients who require special attention.

We think it is necessary to create more awareness among healthcare workers and DHH people themselves about the possible healthcare barriers they may encounter and experience, and - more importantly - about how to avoid or overcome these barriers. The development of healthcare facilities to support DHH people and their healthcare workers, (e.g. the network of specialized mental health facilities in the Netherlands) may be effective but the effects of such facilities should be monitored and evaluated (12).

Conclusion

DHH people experience significantly more physical and psychological difficulties than people in the control group. More extensive use of sign language is related to a reported better health related quality of life. Scores for psychological health were higher (better) in the deaf subgroups than in the hard of hearing subgroups; in contrast to results from other studies, deaf participants in the Netherlands did not report more psychological problems than the control group.

More awareness and knowledge concerning the specific health problems of DHH people is necessary to enable appropriate and adequate healthcare provisions. DHH people and healthcare workers should be alert for co-morbidities and barriers to access of healthcare, be educated in how to recognize and deal with them, and when to consult an expert, specialized services or communication assistance (e.g. text-to-speech- interpreter or sign language interpreter).

Recognizing DHH people as a patient group requiring special attention is the first step towards improving their health.

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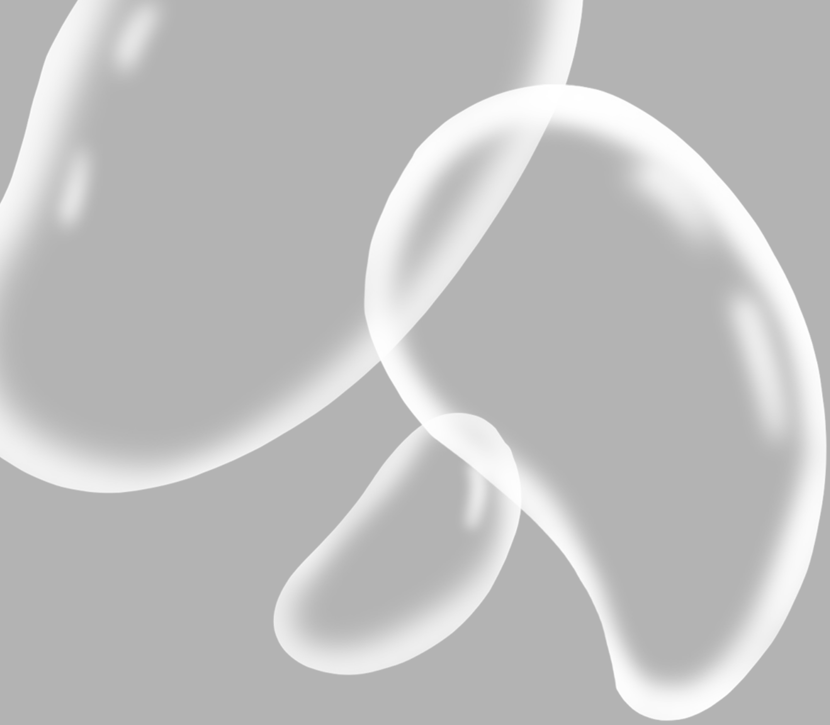

4.3

Deaf Culture features and healthcare - An overview of current knowledge and new insights

Submitted article:

Smeijers AS, Ens-Dokkum MH, van den Bogaerde B, Oudesluys-Murphy AM. Deaf cultural features & healthcare - An overview of current knowledge and new insights

Abstract

This article presents an overview of features of Deaf Culture that may influence the health and healthcare provision of (D)deaf/Hard of hearing (DHH) people. A systematic review was conducted to evaluate this issue and structured interviews were held. Subsequently a large epidemiological study was conducted to evaluate the health of DHH people in the Netherlands. Compared to hearing people, the DHH group experienced a lower health related quality of life (HQoL). Communication barriers, barriers due to less general knowledge and specific Deaf Culture barriers influence healthcare provisions. A more extensive use of sign language and a higher degree of identification with Deaf culture and/or hearing culture appear to be related to a better HQoL. Healthcare workers and DHH people themselves should be acquainted with this information from the point of view of equal rights to good healthcare for all people, as well as for ethical and legal reasons.

Introduction

Organizations of DHH people state that their members often report negative experiences in their contacts with the medical world. These begin during childhood. As a child they are brought to General Practitioners (GPs), pediatricians and audiologists regularly without adequately understanding what is happening to them and why. These negative experiences are reactivated in adult life when they feel that they do not receive and/or understand information from healthcare workers.

Limited access to spoken communication is an obvious barrier to accessing healthcare (Ludders & Bruce, 1987; McEwen & Anton-Culver, 1988). However, DHH organizations and specialized healthcare workers consider that other barriers play an important role in people with prelingual moderate to severe hearing loss as well, namely less general and medical knowledge, different experiences, cultural norms and values which are different to those of hearing people.

Deaf Cultural features

(Sub)cultures are often defined as groups of people who have their own language, ethnohistory and binding social factors. Their shared background is the basis for common social rules, norms and values of this group. All people who are severely DHH are limited in their access to spoken language and are at times excluded from hearing society. Children in special schools for deaf and hard of hearing children are aware of their shared ethnohistory and most DHH people experience binding social factors and personal features resulting from their perceived common social and personal barriers. When Deaf culture is defined in this way, all severely DHH people experience some Deaf Culture features (Kusters, 2013).

People who are deaf and identify with Deaf culture, including for example people who are proud to use a sign language (SL), who are aware of the shared history of the Deaf and who meet regularly, call themselves Deaf or members of the Deaf community (Woll & Ladd, 2003). In this paper the focus is on the influence of Deaf Culture features on the health of and healthcare provisions for DHH persons.

In the literature, DHH people report problems in accessing medical care (Smeijers, Ens-Dokkum, van den Bogaerde, & Oudesluys-Murphy, 2015), perceive a lower health related quality of life (Fellinger et al., 2005; Fellinger, et al. 2007), report delay in visiting the doctor (Steinberg, Barnett, Meador, Wiggins, & Zazove, 2006) and communication barriers during consultation RNID, 2004; Barnett & Franks, 2002; Folkins et al., 2005; Hochman, 2000; Jones, Renger, & Firestone, 2005; Kritzinger, Schneider, Swartz, & Braathen, 2014;

Maddalena, O'Shea, & Murphy, 2012; Pereira & Fortes, 2010; Pfeinkofer, 1994; Smeijers et al., 2015; Steinberg, Wiggins, Barmada, & Sullivan, 2002; Tedesco & Junges, 2013; Ubido, Huntington, & Warburton, 2002; Zazove et al., 1993). Several studies point out that nurses and deaf clients feel that they are not able to communicate effectively with each other due to both language and cultural barriers, comparable to the experiences of and with other minorities (Brink-Muinen et al., 2004).

There is little information available on the influence of Deaf Culture features on healthcare provision and no information about the effect of these features on the health of DHH people. The aim of this article is to create an overview of Deaf culture features that may influence the health of, and the healthcare provision for DHH people. A systematic literature review was done and structured interviews held to evaluate this. Subsequently a large epidemiological study among DHH people was conducted to evaluate the health and Deaf Culture features of DHH people in the Netherlands.

Because people vary greatly in hearing status, we will use the term (D)deaf/ Hard of hearing (DHH) to describe all people who are deaf or hard of hearing and the term Deaf with a capital D to refer to members of the Deaf community or Deaf Culture features (Kuenburg, Fellinger, & Fellinger, 2016).

Methodology

Study group

In this study, which is a part of a larger project, inhabitants of the Netherlands who are DHH and older than 18 years were eligible for entry. The definition "DHH" was based on several self-reported items concerning hearing functioning. The study was designed to avoid inclusion of people with mental or cognitive issues. Participants were recruited through articles and announcements on websites, newsletters of patient groups, magazines, national and local newspapers and websites of Deaf clubs and/or organizations for/of DHH people. General information about the study was provided at gatherings of the Deaf community, symposia for DHH people and at medical conferences. In addition, participants were recruited through snowball sampling and newsletters produced by manufacturers of hearing aids.

Control group

For comparison with the general population in the Netherlands, we used data from the Dutch World Health Organization Quality of Life- Bref scale (WHOQoL-BREF) database (de Vries & van Heck, 2003). Persons were matched for age, sex and level of education.

Research goal

The aim of this study was to gain more insight into the influence of Deaf Culture features on the health of DHH people in the Netherlands.

Research question

Which Deaf Culture features can be encountered when providing or receiving healthcare for or by DHH people? Do these Deaf Culture features influence their perceived Health Related Quality of Life?

Variables/ Statistical information

This is the first inventory of this kind in the Netherlands. Apart from two Austrian studies, no further comparable international data are available. We based our power calculations on these two Austrian studies that included members of the Deaf community and hard of hearing participants (Fellinger et al., 2005; Fellinger et al., 2007). It was calculated that we needed 54 deaf and 189 hard of hearing participants to obtain a power of 0.8 on the WHOQoL-BREF. Our power calculations, database and statistical analysis plan were checked by a statistician prior to executing the study. To minimize the risk of under-powering our study, inclusion of participants was continued for an extra three months after reaching our calculated power. Analyses were performed in accordance with our analysis plan. The outcomes of the DHH groups were compared to those of the general population control group, matched for age, level of education and sex (de Vries & van Heck, 2003).

SPSS software was used to perform statistical analyses. All quantitative analyses were performed independently by two members of the team.

Research methods

Three different research methods were used.

1) A systematic review to identify effects of Deaf Culture features on health and healthcare provision described in literature.
2) Structured interviews with experts about their own experiences with Deaf Culture aspects in medical situations
3) A quantitative assessment of health related quality of life and Deaf/ Hearing acculturation of DHH persons in the Netherlands.

Research techniques

Systematic review to identify what is known about the effect of Deaf Culture features on DHH health and healthcare provision.

The following databases were searched: PubMed, Web of Science, PsycINFO, Academic Search Premier, CINAHL and Embase. The English search terms ‘deaf’, ‘hard of hearing’, ‘hearing impaired’ and ‘Deaf culture’ were used, each in combination with ´healthcare´. The first three search terms were also combined with ‘facilities’. The search was limited to articles published after 1980. Articles written in the English, Dutch or German language were included. These searches resulted in 791 unique articles. All articles were read and assessed independently by two members of the team, differing views were discussed until consensus was reached. Articles on health related features of Deaf culture and common Deaf barriers to healthcare were included, including articles on limited knowledge, linguistic barriers and common customs and values. Articles covering the consequences of these barriers were also included. Articles on deaf education, hearing revalidation, genetic counseling and healthcare services were excluded. 75 articles remained after selection.

The search also resulted in 189 reviews. These were checked for original articles that were not found in the initial search. The references in the already included articles were also checked and discussed by the two team members. This resulted in another 31 articles.

In total 106 articles were found. Since Kuenburg et al., 2016 recently published an overview of the available literature on healthcare access among Deaf people, we will confine ourselves to describing a selection of the literature.

Structured interviews

A set of standard questions were formulated for interviews with experts about their own experiences with Deaf Culture aspects in medical situations. Five representatives of DHH organizations and eight SL interpreters answered these questions. Twenty deaf and hearing healthcare workers from mental health services answered the same questions in a more informal manner. Anecdotal evidence was gathered from healthcare workers, representatives from DHH organizations, interpreters and DHH informants (Table 1). Data from these qualitative interviews were used to help interpret the quantitative results of the questionnaires.

Table 1: Background of informants

Informant number	Role/ position	Methodology
1-7	Sign language interpreter	Structured interview
8	Speech-to-text interpreter	Structured interview
9	Representative of the Dutch association of parents of deaf children (FODOK)	Structured interview
10	Representative of the Dutch Federation of Hard of Hearing (NVVS)	Structured interview
11	Representative Dutch Federation of Hard of Hearing (NVVS)	Structured interview
12	Representative of the Dutch association of the Deaf (Dovenschap)	Structured interview
13	Representative Deaf Welfare Foundations (Doven Welzijns Stichting)	Structured interview
14 & 15	Psychologist working with DHH people	Anecdotal evidence
16-18	MD working with DHH people	Anecdotal evidence
19-21	Administrators working with DHH people in medical situations	Anecdotal evidence
22-27	Nurses working with DHH people	Anecdotal evidence
28-33	Social workers working with DHH people	Anecdotal evidence
34-40	Visitors of Deaf clubs	Anecdotal evidence

(DHH= Deaf or Hard of Hearing)

Standardized questionnaires

Questionnaires are reliable only when provided in a person's first language. For this reason we translated, adapted and tested all our test material into Sign Language of the Netherlands (NGT) (Smeijers, van den Bogaerde, Ens-Dokkum, & Oudesluys-Murphy, 2014). All questionnaires were translated into two versions of NGT according to a forward- backward translation protocol (Smeijers et al., 2014). A written version and a sign supported Dutch (SSD) version of the questionnaire were also provided.

We used Unipark software to manage the questionnaires in an online environment (Hocker, 2010; Unipark, 2015).

Participants filled out questionnaires at home on their own computer. People who did not possess enough computer skills to fill out the questionnaire at home could receive assistance at special meetings. Assistance was given by three members of the research team who were trained to provide technical assistance only; no assistance was given with regard to the content.

During the first phase of the study the questionnaire was placed within a secure internet environment. After signing a written consent form, participants received a personal log-in for the questionnaire. During the second phase of the study this was altered because the procedure seemed to hinder participation in the study. Therefore, the questionnaire was placed in a secure environment without log-in authorization, enabling people to give online consent instead of written consent. Data were checked to prevent duplications.

Research instruments

The health related quality of life was assessed using the World Health Organization Quality of Life- Bref scale (WHOQoL-BREF). The WHOQoL-BREF is an internationally standardized, methodologically strong questionnaire. It consists of four subdomains, viz. physical, psychological, social and environmental QoL (Group, 1998).

The Deaf Acculturation Scale (DAS) is a 58-item bimodal, bicultural instrument. It consists of two overall acculturation scales: a deaf acculturation scale (DASd) and a hearing acculturation scale (DASh) (Maxwell-McCaw & Zea, 2011). The DAS is a validated scale that provides information about the cultural status of DHH persons. Having a different cultural identity from the majority in society may negatively affect communication (Schouten, 2006; Smeijers & Pfau, 2009). The DAS may be used to evaluate such effects among DHH people.

The participants also filled out an epidemiological questionnaire which included questions about age, sex, audiological status, audiological features of parents, amplification, socio-economic features, level of education, language skills and demographics. Participants were also asked whether or not they used a sign language, i.e. Sign Language of the Netherlands (NGT), and to what extent: mainly NGT, mainly sign supported Dutch (SSD), some NGT and/or SSD alternating with Dutch, or Dutch only. This questionnaire may be obtained from the corresponding author.

In this research project we collected a large amount of quantitative and qualitative date. In this article we will present the data of this project that relate to Deaf Culture.

Research sample

The questionnaires were filled out by 274 DHH people. Characteristics and demographics are shown in Table 2.

The audiological functioning of the analysis group was based on self-report; participants had to answer questions about their own perceived hearing status and functional hearing, including questions such as ability to understand speech in a group conversation, understanding speech in a one-on-one conversation and the degree of hearing loss in decibels (dB). The analyses will be described in the result section.

Ethics

The research protocol was assessed and approved by a local scientific committee and the regional Leiden University Medical Centre medical ethical committee prior to the start of this study.

Table 2: Participant characteristics.

	Deaf	SHoH	MHoH	Control group
Year of birth				Population based control group was matched for age, gender and level of education for all three DHH groups separately.
• 1985-1993	10.1%	4.8%	2.3%	
• 1975-1984	9.0%	8.9%	2.3%	
• 1965-1974	16.9%	12.1%	16.3%	
• 1955-1964	17.9%	19.4%	16.3%	
• 1945-1954	30.4%	35.4%	30.2%	
• 1935-1944	11.2%	16.2%	18.6%	
• Before 1935	4.5%	3.2%	14.0%	
Gender				
• Female	71.7%	71.2%	52.3%	
• Male	25.0%	28.1%	45.5%	
• Unknown	3.3%	0.7%	2.2%	
Level of education				
• Prim./ secondary school only	29.9%	13.6%	11.6%	
• Junior secondary technical school	8.9%	9.6%	7.0%	
• Vocational training	26.7%	32.8%	34.9%	
• Bachelor degree	26.7%	34.4%	39.5%	
• Master degree	7.8%	9.6%	7.0%	
Employment	66.7%	53.2%	60.6%	
Have cochlear implant	34.9%	12,2%	2.0%	
Language use				
• Primarily SL	21.8%	0.7%	2.3 %	
• SSD or SSD/SL and spoken language	47.8%	11.3%	6.8%	
• Spoken language only	30.4%	88.0%	90.9%	

In the Netherlands people retired at age 65 up to 2014. Therefore people born before 1945 were excluded from job percentages.

Participants filled out the questionnaires in 2011 and 2012.

(SL= sign language, SSD= sign supported Dutch, SHoH= severe hard of hearing, MHoH= mild/ moderate hard of hearing)

Results

Barriers described in the literature and in structured interviews.
In general, DHH people may face three types of barriers: 1) communication barriers, 2) barriers due to reduced general and medical knowledge, 3) Deaf Culture barriers. These barriers are discussed below.

Communication barriers
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 (Kuenburg et al., 2016). However, this is not the only communication barrier faced by DHH people as patients: they also perceive basic communication problems due to linguistic differences between spoken and signed languages.

A direct one-to-one translation from one language to another is never possible (Temple et al., 2004). This is particularly true for the translation of spoken language into sign language and vice versa. Translating speech into sign language or vice versa may raise semantic issues when a hearing speaker communicates with a Deaf sign language (SL) user. A practical example of this is the confusion in understanding the results of a medical test. In many sign languages, the word ‘positive’ is closely linked to ‘good’. Therefore, it is difficult for the client using SL to understand that something that is positive, such as a test result, may be an undesirable outcome. Like in other linguistic minority groups, there are reports of some SL users who believed that being HIV-positive was desirable and that a chest x-ray positive for cancer was a good thing. Hearing healthcare workers need to be aware of this mismatch and try to avoid it or explain it (Stebnicki et al., 1999).

Another example from discrepancies between Dutch and NGT is the verb ‘must’. In spoken Dutch the phrase ‘you must…’ can be used in a liberal way (‘you could’), as a non-binding advice. Within NGT ‘you must…’ is reserved for situations where there is no choice (Giezen, 2001). Therefore, an NGT user might be annoyed when a hearing physician tells him/her what she/he ‘must’ do instead of giving options. An American example of miscommunication in written language caused by differences in syntax and semantics between spoken English and American Sign language (ASL) is illustrated below.

Example 1:

Spoken language:	‘You may need operation’
ASL:	‘You (in) May need operation

In many sign languages, as in ASL, prepositions like 'in' are not explicitly signed. Due to this fact and the differences in word order in both languages, an SL user may understand 'You need an operation in May' when the physician writes down 'You may need an operation' (Meador & Zazove, 2005).

Sign languages are not solely manual languages. In addition to the hands, SL uses facial expressions and body postures as grammatical structures. Such use of the body and face may result in healthcare professionals who are not aware of these facts, misdiagnosing an expressive SL user as having tics, inappropriate affect, personality or mood disorder (Philips, 1996; Barnett, 1999; Pollard, 1994; Landsberger et al., 2010; Steinberg, 1991).

In addition, the pragmatic rules of conversational structure may differ between sign languages and the local spoken languages. Spoken American communication for example, works its way up to the main point and then concludes, while ASL starts with the main point and winds down. Therefore, a hearing physician may think communications are finished while the DHH patient is still 'winding down' the conversation. Due to these pragmatic differences, physicians explaining treatment recommendations to DHH patients may feel that the patient is asking the same question over and over again (Meador & Zazove, 2005).

Barriers due to limited general and medical knowledge

Limited exposure to physical and health information in schools for deaf children contributes to the limited basic knowledge often encountered in many deaf adults (Barnett, 1999). Education mainly focuses on acquisition of spoken and written language, often at the cost of general knowledge, as is evident from example 2.

Example 2: 'We spent 2 weeks learning to say 'guillotine' (Solamon, 1994)

A deaf woman describes learning about the French revolution in school.

Low literacy may also play a role. Information from newspapers, magazines, written internet pages and television captioning is less accessible to DHH people than it is to hearing people (Barnett, 2002; McKee, Paasche-Orlow, & et al., 2015; Smeijers, Ens-Dokkum, van den Bogaerde, & Oudesluys-Murphy, 2011; Smith, 1992).

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 medical family history and their own early childhood illnesses by overhearing family conversations or their parents answering questions posed by their physician (incidental learning). DHH children cannot overhear these conversations and later, as adults, may not know the answers to related questions (DiPietro et al., 1981). They also may not realize that this information is important to their physician (Barnett, 1999).

Most of the articles on limited knowledge in DHH people focus on one specific topic such as sex education (Fitz-Gerald & Fitz-Gerald, 1982), HIV risk behavior (Baker-Duncan et al. 1997; Bat-Chava et al. 2005; Doyle, 1995; Goldstein et al., 2010; Heiman et al. 2015; Hanass-Hancock et al., 2010; Joseph et al., 1995; Luckner & Gonzales, 1993; Mallinson, 2005; Pfeinkofer, 1994; Bares, 1999; Smeijers et al., 2015; Woodroffe, et al. 1998) or prevention and cancer screening programs (Pinkenson, 1994; Orsi et al., 2007; Wollin & Elder, 2003).

Recently a study by pharmacists showed that many ASL users in the DHH population still perceived community pharmacists in a dispensing role and lacked knowledge on other services offered in this setting. The study suggests that safe use of medications in DHH people may thus be compromised (Ferguson & Liu, 2015).

Many informants in our study mentioned that Deaf people have difficulties in separating main issues from side issues. Due to the combination of less knowledge about medical situations and not knowing what is important for the doctor to know, it is often perceived that DHH people 'talk' too much during history taking (report in structured interviews). Even when consulting a general practitioner for a minor complaint, they tend to tell the story of their whole life. On the other hand, some relevant information might be left out.

Physicians tend to adapt the amount and level of the information they present to the presumed educational level of the individual patient. Due to lack of knowledge, 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 the information he or she gives to this misinterpreted level of education, the chance that inadequate information is given to the patient is increased (Smeijers & Pfau, 2009). 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.

Specific Deaf Culture barriers

Meador & Zazove (2005) described five Deaf Culture barriers in healthcare provision for the Deaf: linguistic accommodations, lack of trust in the 'hearing world', need for confidentiality, respect for intelligence and dissemination of information. We have categorized ‘linguistic accommodations’ as a communication barrier, so we will not describe this one here. From our literature search and the interviews, it appears that ‘information processing’ and ‘manners’ may be also be added to this list. We will describe these six Deaf Culture barriers below.

Information processing.

Deaf community members are more likely to get information from each other than from formal information sources (Kennedy & Buchholza, 1995). This may lead to problems, because the community does not always receive complete information or the information may be only partially understood. (Luckner & Gonzales, 1993) showed for example, that 70% of DHH adolescents did not know that HIV cannot be transmitted by giving blood, only by receiving it. Another example appeared during our structured interviews: Deaf members of a local Deaf club had prepared themselves for announced new legislation, but this had already been cancelled before it could be put into practice.

Manners

Clearing one’s throat or politely saying “excuse me” will not attract a deaf person’s attention. In the Deaf community people rely on touch and vision rather than hearing. 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, stomping, and banging can seem socially inappropriate (Barnett, 1999).

A regularly reported difference in manners recounted in our structured interviews is the process of greeting. The informants mentioned that Deaf people in the Netherlands are more physically orientated than hearing people. Within the Deaf community embracing one-another is a very common way of greeting, even when people hardly know each other, e.g. a healthcare worker; this is not 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. Because face-to-face communication is valued, the relatively short “goodbye” typical of conversation closing by hearing people, including physicians, may be considered rude by Deaf people (Hall, 1983).

Lack of Trust

Severely DHH children lack access to (ambient) information in hearing surroundings like a health facility. The experience that things happen to them without having been informed about what is going to happen and why, makes them more sensitive to feelings of exclusion as adults. However, they also continue to accept this as a fact of life; Both in our structured interviews and in the literature, it was stated that DHH people are less assertive when visiting their physician.

That these experiences influence healthcare provision is illustrated by figures from Australia and North America, which show similar participation rates in preventive screening programs to hearing people, while most deaf participants do not understand what the exact purpose of these screening programs is (Orsi et al., 2007). 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 is (Orsi et al., 2007).

Within the Deaf community, emphasis is placed on information access. 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 (Barnett, 1999).

Many of our informants in the structured interviews stated that Deaf people judge their physicians differently than hearing people do. As it is even more difficult for Deaf people to judge the medical skills of a physician than for hearing clients, his/her reputation is, even more often than among non-Deaf people, based on communication skills and willingness to take time to communicate with the Deaf person.

Due to incomplete schooling and communication barriers Deaf people are usually not as good in discussions and debates as hearing persons and nuances are easily lost. For example, if one department of a hospital is thought to deliver poor quality care then all other departments are also thought to deliver poor quality. A physician is considered either very good or very bad, there is no in-between.

Small community and need for confidentiality

The Deaf form a closely-knit group and many DHH people often interact socially with other DHH people (Orsi et al., 2007). Confidentiality is very important (Pfeinkofer, 1994). This is why Deaf people may be even more reluctant than hearing people to discuss sensitive topics such as psychological problems or HIV transmission (Pfeinkofer, 1994; Anthony, 1992). Several articles report that the Deaf community has a negative attitude towards HIV/AIDS patients (Pfeinkofer, 1994; Woodroffe et al., 1998). Fear of isolation from their own community may prevent them from using medical and social services (Pfeinkofer, 1994).

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.

Respect for Intelligence

DHH people, including those with mild hearing loses, are often treated as if they have lower intelligence. Due to fewer opportunities for incidental learning, DHH people may have less medical knowledge than their hearing peers, which contributes to this misconception.

It would be helpful if healthcare workers are aware of this issue and make sure they offer sufficient information at the right cognitive level.

Dissemination of Information

DHH people are regularly approached for research participation, but research results are often presented in a way which is incomprehensible for DHH people. Not knowing what is done with the outcome of their effort as well as their fear of misuse of data makes many DHH people reluctant to participate in research projects, especially those run exclusively by non-DHH researchers.

Results of Health Related Quality of Life and DAS questionnaires

Two hundred and seventy-four DHH people filled out the questionnaires. Figure 1 shows the audiological characteristics of the respondents based on self- report. Other characteristics and demographics are shown in Table 2.

We used two different analysis methods to distinguish between respondents:

1) On the basis of self-reported hearing function. On the basis of self-reports 72 people identified as deaf and 108 as severely hard of hearing (HoH).
2) Based on both self-reported hearing function and reported degree of hearing loss (Figure 2). Using the analysis based on reported hearing loss 92 people were considered functionally deaf and 127 people severely HoH.

Since the difficulties and barriers that a DHH person may experience may vary based on the age of onset and the amount of the hearing loss, we identified seven subcategories (Figure 2 and Table 3). One third of our participants were born DHH or became DHH before the age of five years, 20 % of the participants became DHH after the age of five but before the age of 21. The other 50% became DHH at a later age.

As the main outcomes did not differ between analysis groups 1) and 2), we will only present the analysis based on self-reported hearing function (group 1).

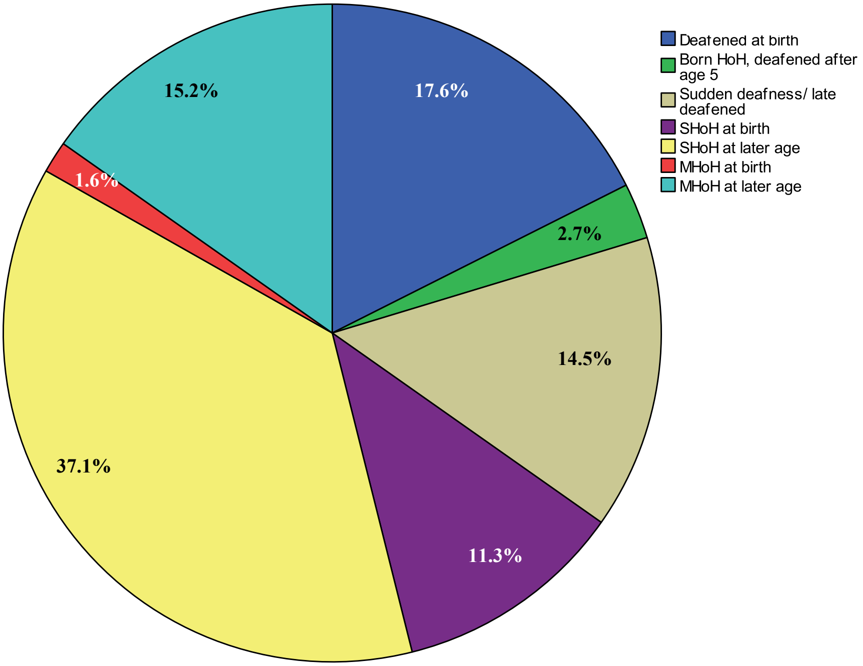

Figure 1: DHH subgroups.
HoH= Hard of hearing, SHOH= Severe hard of hearing, MHOH= Mild/ moderate hard of hearing

Table 3: Participant characteristics, mean age of subgroups.

Hearing status	N	Mean age	Std. Deviation
Deafened before age 5	43	50.3	16.97
Born hard of hearing, deafened after age 5	6	54.5	18.59
Sudden deafness/late deafness	37	55.9	12.68
Severe hard of hearing before age 5	28	42.0	16.21
Mild/moderate hard of hearing before age 5	4	58.8	13.28
Severe hard of hearing after age 5	93	58.8	11.25
Mild/moderate hard of hearing after age of 5	38	60.7	14.64

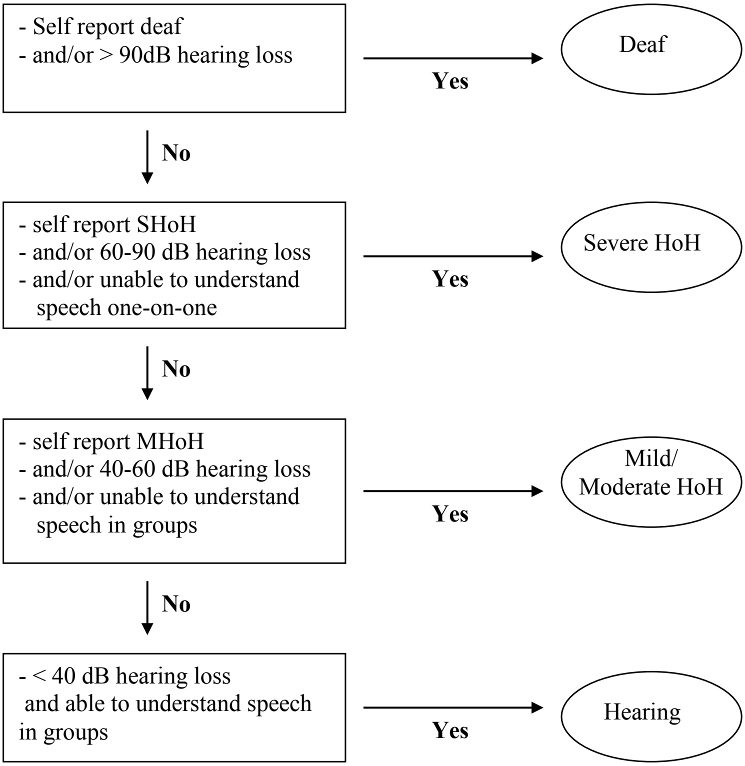

Figure 2: Classification of amount of hearing loss.
dB loss is measurement report of best ear.

WHOQoL-BREF

Scores for physical wellbeing and scores on social domains were convincingly and significantly lower than in the population based control group (de Vries & van Heck, 2003). The HoH groups also reported significantly lower (worse) scores for psychological wellbeing (Tables 4a+b).

Significantly positive correlations were found between the physical as well as the psychological QoL and the use of sign supported Dutch/ Sign Language of the Netherlands: more extensive use of supporting signs/SL was related to higher (better) psychological/ physical QoL scores.

DAS

In total 235 people, 60 Deaf and 175 HoH, filled out the DAS questionnaire. Of this group, 118 persons have a bicultural score, 54 persons have a hearing acculturated and 14 a deaf acculturated score, while 48 are marginally acculturated. Remarkably, the deaf participants showed (highly significant) better acculturalization scores than the HoH participants (Table 5, Table 6). Eleven participants reported having deaf parents. This number is too small for reliable statements about the influence of parental hearing status on the acculturalization of our participants.

A positive correlation was found between all four quality of life subscales, and both DASd and DASh. Most of these correlations were highly significant (Table 6). This means that a higher degree of identification with Deaf culture and/or hearing culture contribute equally to a higher health related QoL. No relationship was found between participation in social activities or membership of the Deaf community and QoL outcome.

The determination coefficient (R2) for all correlations is given to show the extent of the correlation (Table 6). Both quality of life and extent of acculturalization are conditions that are influenced by many different factors. In this study was found that 2.8% - 11.7% of a person’s quality of life was influenced by his or her degree of acculturalization (or vice versa).

Table 4a: Means and standard deviations (in brackets) for WHOQOL-BREF domain scores of DHH.

WHOQOL-BREF scale	Deaf	P Deaf vs GPop	SHOH
Physical	62.13 (17.58)	0.0413×10^{-12} **	55.84 (18.47)
Psychological	68.18 (13.29)	0.479	62.78 (14.11)
Social	67.78 (19.50)	0.036*	65.71 (19.21)
Environmental	68.28 (14.16)	0.0985×10^{-3}**	71.56 (16.62)

Domain scores range from 0 to 100. Higher scores correspond with higher quality of life. Means and standard deviations in the table are unweighted. P values are weighted for sex, age and education level.

Table 4b: Means and standard deviations (in brackets) for WHOQOL-BREF domain scores of DHH subgroups.

WHOQOL-BREF scale	Deaf before age 5	P Deaf before age 5vs GPop	SHOH before age 5	P SHOH before age 5 vs GPop
Physical	63.85 (17.28)	0.001*	56.40 (18.07)	0.012×10^{-3}**
Psychological	69.56 (13.61)	0.11	62.94 (13.00)	0.335
Social	69.27 (81.29)	0.56	72.14 (13.15)	0.984
Environmental	68.52 (14.25)	0.002*	73.32 (15.15)	0.200

Domain scores ranch from 0 to 100. Higher scores correspond with higher quality of life. Means and standard deviations in the table are unweighted. P values are weighted for sex, age and education level.

P SHOH vs GPop	MHOH	P MHOH vs GPop
$0.0276x10^{-24}$**	50.26 (18.00)	$2.28x10^{-12}$**
$0.624x10^{-6}$**	59.00 (11.33)	$0.285x10^{-6}$**
$0.2266x10^{-3}$**	59.85 (25.10)	0.03*
0.062	69.39 (16.01)	0.04*

The asterisks in the table indicate the significance of the weighted data compared to hearing controls[19] (*p<0.05, **P<0.001)

(SHoH= severe hard of hearing, MHoH= mild/ moderate hard of hearing)

Deaf after age 5	P Deaf after age 5vs GPop	SHOH after age 5	P SHOH after age 5 vs GPop	L/MHOH after age 5	P MHOH after rage 5 vs GPop
59.62 (17.58)	$0,034x10^{-3}$**	56,03 (16,84)	9.064x10-^{15}**	50,00 (17,05)	$1.6708x10^{-9}$**
67.71 (12.38)	0.549	63,40 (11,26)	$0.512x10^{-3}$**	59,76 (11,10)	$0.077x10^{-3}$**
68.52 (21.56)	0.859	64,67 (18,23)	0.003*	61,18 (22,09)	0.008*
69.23 (13.59)	0.04*	72,28 (14,62)	0.017*	69,57 (15,01)	0.011*

The asterisks in the table indicate the significance of the weighted data compared to hearing controls[19] (*p<0.05, **P<0.001)

Table 5: Mean scores of participants on DASd and DASh scale. Higher scores correspond with higher grade of acculturalization.

	N	Mean score DASd	Mean score DASh
Deaf participants	60	2.896619	3.029726
HoH participants	175	2.477434	2.650429
Deaf vs HoH participants		P= 4.7x10^{-11**}	P= 5.3x10^{-9**}
Deaf before age 5	42	2,987823	3,115125
HoH before age 5	35	2,612082	2,764925
Deaf after age 5	36	2,556429	2,746296
SHoH after age 5	93	2,464772	2,642458
MHoH after age 5	34	2,416078	2,513361

The asterisks in the table indicate the significance of the weighted data compared to hearing controls[19] (*$p<0.05$, **$P<0.001$)

(SHoH= severe hard of hearing, MHoH= mild/ moderate hard of hearing, DASd= Deaf acculturalization, DASh= Hearing acculturalization)

Table 6: Correlation between Deaf acculturation scale and QoL.

	Deaf acculturalization (DASd)		**Hearing acculturalization (DASh)**	
	P-value	**R^2**	**P-value**	**R^2**
Physical QoL	7.68x10^{-5}**	0.061	4.63x10^{-6}**	0.081
Psychological QoL	6.92x10^{-7}**	0.094	2.62x10^{-8}**	0.117
Social QoL	5.55x10^{-4}**	0.047	0.003*	0.035
Environmental QoL	0.036*	0.018	0.059	0.014

The table shows the p values and the determination coefficients (R^2) of the correlation between amount of culturalization measured with the DAS scale and reported quality of life on the WHOQoL-BREF (*$p<0.05$, **$p<0.001$). All correlations are positive: a higher degree of culturalization corresponds with a higher quality of life.

Discussion

Little information is available on the effects of the barriers described above on access to healthcare. Several studies reported that DHH people have a lower perceived mental and physical quality of life than hearing people (Fellinger et al., 2005; Fellinger et al., 2007), but until now there have been no quantitative reports on the possible causes. This study found a positive correlation between all four quality of life subscales and both DASd and DASh. It was also found that more extensive use of sign language was related to a higher (better) psychological/physical quality of life (QoL) scores. Both relationships are continuous: the more sign language and the more acculturalization a person has, the higher the score on the QoL scales.

It could be hypothesized that people who experience better health, have higher acculturalization scores because they tend to participate in social activities more frequently, but our data did not support this explanation.

In contrast to other studies, deaf participants in the Netherlands did not report more psychological problems than the control group. These finding might be caused by methodological issues like the choice of instrument or participant recruitment but the WHOQoL-BREF was especially chosen because of its ability to reveal the internalizing problems usually described in DHH and we had no reason to believe that psychologically healthy people were overrepresented in our sample.

One possible explanation may lay in the fact that our HoH participants showed significant lower levels of acculturalization on both the DASd and the DASh scale. HoH often report that they feel they neither belong to the hearing community nor to the Deaf community. This feeling of being left out may cause a lower psychological QoL.

Another explanation for the better scores for psychological wellbeing of deaf people than of hard of hearing people might be found in the provision of specific mental healthcare facilities in the Netherlands. There is an extensive network of specialised psychological and psychiatric facilities for the deaf. No research has been done to evaluate the effect of specialised facilities, but it is possible that the previous extensive availability of these services has influenced the finding of a better perceived psychological quality of life of deaf people, compared to the hard of hearing participants with limited access to specialised healthcare facilities, and compared to deaf people in other countries (Fellinger et al., 2005).

A third explanation may be related to the fact that, until recently, children with a mild hearing loss were not diagnosed at a young age. They often started school without knowing about their hearing loss and were commonly wrongly accused of being stupid or unwilling to listen. This may have lowered their self-image and their psychological QoL accordingly.

Acculturalization is a personal process, which is routed differently in each individual. A DHH person may be influenced in different ways by family, peers and Deaf/deaf and/or hearing role models. Therefore, not all of the described Deaf Culture features will apply to all Deaf people, and not every possible barrier mentioned in the results will apply to every DHH person. There are many possible reasons for DHH people not to identify with the Deaf community, even when their hearing loss is profound. Despite this, all DHH people may experience (some of) the Deaf Culture barriers described above. For example, problems due to lack of knowledge also occur in severely DHH people who do not consider themselves to be Deaf and some of the communication barriers may occur even when people become profoundly DHH at a later age.

Deaf people, like non-Deaf people might be reluctant to discuss sensitive topics. Fear of isolation from their own community may prevent deaf persons from using medical and social services (Pfeinkofer, 1994). Some SL users may also be reluctant to use an interpreter, especially if the interpreter is well known in the Deaf community, because they feel anxious about issues of confidentiality. However, patients cannot make informed choices, and assessments may not be properly carried out without an interpreter (Bogaerde & de Lange, 2014; McAleer, 2006). More insights are needed about which topics are considered delicate and which are not within a Deaf community because these may differ from those within the local hearing community.

Since doctors are legally responsible for obtaining informed consent from their patient, it is their duty to optimize communication in every possible manner, to be acquainted with these barriers and to insist on using a sign language or text-to-speech- interpreter when required.

Apart from studies describing HIV and substance abuse and some reports on metabolic syndrome, we found hardly any studies describing the incidence or prevalence of specific diseases or conditions in DHH people. More knowledge about the specific health problems of DHH people is necessary to enable adequate healthcare provision.

Conclusion

DHH people experience more physical and psychological difficulties than hearing control groups. Communication barriers, barriers due to less general knowledge and specific Deaf Culture barriers influence healthcare provisions to deaf and severely hard of hearing patients. Use of sign language and a higher degree of identification with Deaf culture and/ or hearing culture is related to a better reported health related quality of life.

To avoid medical, ethical and legal problems, healthcare workers and DHH people themselves should be acquainted with these barriers, be trained how to recognize and overcome them, and be informed when to consult an expert, specialized services or ask for assistance (e.g. speech-to-text interpreter or sign language interpreter).

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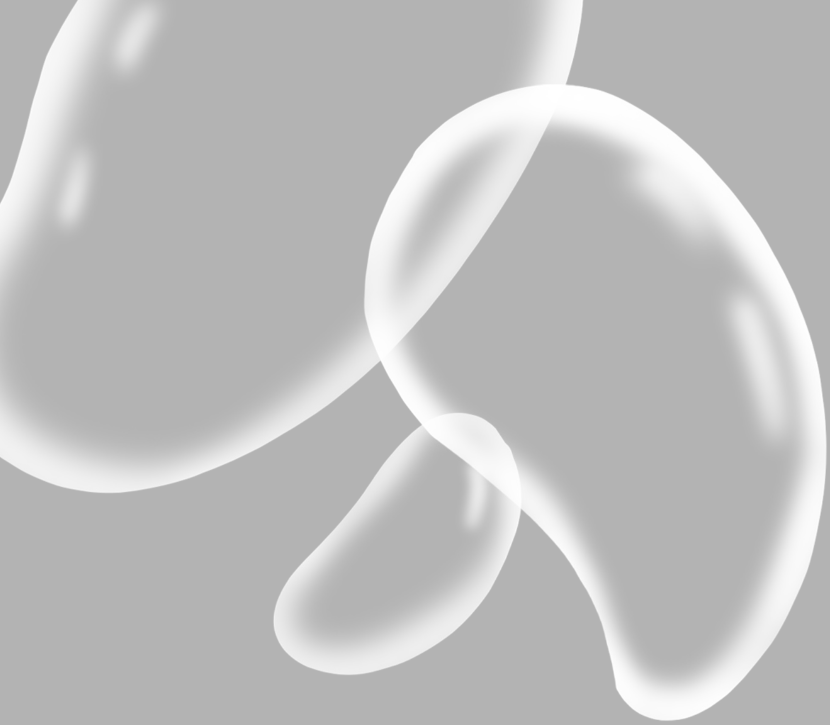
Healthcare facilities for deaf and hard of hearing people



5.1

Availability of specialised healthcare facilities for deaf and hard of hearing individuals

Published article:

Smeijers AS, Ens-Dokkum MH, van den Bogaerde B, Oudesluys-Murphy AM. Availability of specialised healthcare facilities for deaf and hard of hearing individuals. International Journal on Mental Health and Deafness, 2018: Volume 4, No. 1. p 14-27

Abstract

Context: To allow a medical consultation to proceed successfully, it is essential that physicians are aware of the linguistic and cultural backgrounds of deaf and hard of hearing individuals (DHH) and related communication aspects. Some specialised healthcare facilities have emerged to respond to the specific needs of people who are DHH.

Objective: This study aims to provide insight into the various types of general healthcare facilities available for DHH individuals. By sharing and comparing experiences and results improvements can be made.

Design, Data Sources and Study selection: A systematic review of the literature on specialised healthcare for DHH people was performed. The following databases were searched: PubMed, Web of Science, PsycINFO, Academic Search Premier, CINAHL and Embase. After independent extraction per article by two readers, fifteen articles were included in the systematic review. As it appeared that not all existing locations of facilities of which we were aware were described in the literature, we expanded the data collection with internet searches, specific literature searches and unstructured interviews.

Results: Some countries have developed facilities to meet the needs DHH people. Experts and patients' groups report that the perceived quality of healthcare and health education in specialised healthcare settings is higher compared to regular healthcare settings. Two projects undertaken to improve the health related knowledge level of DHH people, proved to be effective.

Conclusion: Some facilities or combinations of facilities are used in different countries to attempt to meet the needs of DHH patients. These facilities are rarely described in the scientific literature. Further development of specialised healthcare facilities for DHH patients, which should include high quality studies on their effectiveness, is imperative to comply with medical ethical standards and respect the human rights of DHH people.

Introduction

Deaf and hard of hearing (DHH) patients have special needs which should be met to ensure they are able to make optimal use of the health system. Several countries have developed, or are developing, healthcare facilities and technical support facilities to improve medical access for DHH. Many of these facilities start locally, but no overview exists of what kind of facilities are available and where they are available. This study aims to provide more insight into the general healthcare provision for DHH and the various types of facilities available to support this healthcare provision. This overview enables individual healthcare workers to share experiences and improve healthcare.

In this article the group of people referred to by the term DHH includes people who are born deaf or severely hard of hearing or become so in the first years of life, people who become deafened when suddenly losing all or most of their functional hearing after the acquisition of spoken language and hard of hearing people with hearing loss ranging from mild to severe, who retain some residual hearing. People who are severely DHH from a very young age may consider themselves part of a cultural and linguistic minority, the Deaf community, which is described as Deaf with a capital D. A shared history and language creates a strong bond between members of this community and for many, this community is an important information resource. This group used to and may still develop low literacy skills. That is why writing down medical information for Deaf patients may be ineffective[1,2]. A care provider using sign language (SL) is to be preferred for this group of patients.

People who become DHH after the first years' of life or are mildly DHH will continue to identify with the hearing community and use their original spoken language. They usually communicate through spoken and written language. They retain some residual hearing and are likely to use hearing aids. Lip-reading, audio induction loops and text-based facilities such as speech-to-text interpreters may also be used. For reasons of readability we will only distinguish between DHH subgroups when this is necessary for correct understanding of the information. Although these DHH subgroups differ from each other, they share the experience that appropriate medical care is not easily accessible because their communication needs, and sometimes cultural needs, are not appropriately met.

There are several indications in the literature that healthcare needs of DHH people differ from hearing control groups. They also report difficulties which are expressed as fear, mistrust and frustration in accessing healthcare[3, 2]. Several barriers hinder the access of DHH patients to healthcare facilities[3, 4].

DHH adults often have limited knowledge concerning health and disease[5, 6]. Restricted exposure to many topics in schools for DHH children contributes to this[7]. Most DHH people do not have access to 'ambient information', they do not overhear conversations or hear radio and television announcements[5,8,9], and low literacy is also a factor in people who are severely DHH from a young age[1]. Information from newspapers, magazines, internet and television captioning is less accessible than it is for hearing people. Thus, DHH adults have limited access to information that many hearing adults would consider common knowledge [5]. Healthcare workers often assume that DHH patients can understand them by lip-reading. However, not all DHH learn to lip-read and even a highly skilled lip-reader can only 'read' 30-40 percent of spoken language by watching the lips of a speaker, the other 60 percent has to be guessed[10]. Since many unfamiliar words are used during a medical consultation, this mode of communication has been proven to be inadequate[2,11].

Since the special needs of the DHH are related to both cultural and linguistic barriers, they are often compared with other minority groups in the literature[5,12,13]. Physicians are not aware of these similarities which often cause communication difficulties. DHH people frequently report that physicians do not understand them[14-16] and physicians are even less likely to try to repeat explanations than when communicating with immigrants[16]. As a corollary to this, DHH people are the only non-native speakers of the local spoken language who may be judged to be mentally retarded if they are incapable of composing a grammatically correct spoken sentence[16].

Effective communication with DHH patients is important in healthcare, as inadequate communication may lead to wrong diagnoses and misguided therapy [17,18]. Physicians are often not sufficiently prepared for caring for DHH patients as academic curricula do not include the necessary competences to meet the needs of this population[19]. Healthcare facilities and technical support facilities are being developed to improve medical access for these patients. Most of these facilities focus on meeting communication needs, some also meet cultural needs.

The main objective of this study is to obtain insight into the various general health facilities available to provide healthcare that complies with the special needs of DHH. Mental health facilities for the DHH have been described extensively [4], therefore, in this article, the information on mental health is restricted to the influence of mental healthcare on general healthcare and vice versa.

Methodology

Various strategies were used for data collections. Primarily a systematic review of scientific literature on this topic was conducted. A PICOS search to evaluate existing specialised healthcare facilities left us with no inclusions (the following criteria were used: Patient: all DHH, Intervention: specialised healthcare facilities, Comparator: regular healthcare provision, Outcomes: any type of outcome measurement, Study: all study types). Therefore we extended the search to an inventory of all existing facilities, including all articles describing any, structurally available, specialised healthcare facilities. As it appeared that not all existing locations of facilities of which we were aware were described in the literature, we expanded this with internet searches and unstructured interviews. During this study the systematic review was updated regularly. Our first systematic review was conducted in 2011, the last update was done in July 2016.

Systematic review

Criteria for considering studies for this review.

Types of studies: All study types were included. We excluded people with intellectual disabilities and deaf blind people. Types of participants: Participants were DHH persons of any age, gender and region of origin. We excluded people with intellectual disabilities and deaf blind people. Types of interventions: Any strategy with the primary intent of improving healthcare provision for DHH. Articles on deaf education, hearing revalidation, genetic counselling, non-institutionalised mental healthcare and Deaf culture were excluded.

Search methods for identification of studies.

Database searches: We conducted searches for articles in electronic databases. We also undertook hand searching the reference lists of reviews and included articles.

Electronical database searches: The following databases were searched: PubMed, Web of Science, PsycINFO, Academic Search Premier, CINAHL, Embase and Google scholar. The search terms ´deaf´, ´hard of hearing´ and ´hearing impaired´ were used, each of them in combination with ´facilities´ and/ or ´healthcare´. Detailed search strategy available from authors.

Searching other electronical sources: A systematic internet search was done using the same search terms as the database search plus ´remote interpreting´ ´remote online interpreting´, ´speech-to-text interpreter´, and/ or ´captions´.

A specific internet search was done to identify additional facilities that were not described in scientific literature. Information provided by the World Federation of the Deaf website, the European Forum of Sign Language Interpreters and the World Association of Sign Language Interpreters was used to identify countries where facilities or SL interpreters are available for DHH people. We specifically searched the internet for more information on possible healthcare facilities available in these countries. If necessary, representatives of deaf organisations were contacted by email. This specific internet search provided us with information on facilities mainly for people who were deaf(ened) from an early age, in Australia, New Zealand, Romania, Thailand and some countries in the Middle-East. No information about facilities for people who became DHH at an older age (as adults) was found with this strategy.

Hand search: We searched the reference lists of all reviews found and of all included articles. We made contact with experts in the field to identify any relevant unpublished or grey literature. One of the authors (AS) spoke with participants of five special interest group meetings and congresses of the European Society of Mental Health and Deafness (2006-2017) about specialised facilities available in their countries. These were unstructured interviews, where written notes were taken. All interviewees were healthcare workers and came from the following countries; Austria, Brazil, Canada, France, Germany, India, Israel, Italy, Norway, Poland, South Africa, Spain, Sweden, Switzerland, United Kingdom and United States of America.

Participants were asked about the existence of inpatient and outpatient facilities in their countries. If these existed, participants were asked whether these were structural or project based, how the facilities were financed and if these were available to all DHH people in the whole country or only in a specific region. Besides this, questions were asked about sign interpreting and speech-to-text facilities in their country. All participants were asked if they also had information on facilities outside their own country. Through these contacts we were able to gather information on facilities in Australia, Egypt, Japan, Mexico, Czech Republic, Slovakia, Croatia, Serbia and Greece.

When the informants responded that they were aware of specialised facilities, they were asked for written data to support their information. In all cases the internet and the literature were searched for data to support their information. If necessary, these facilities were contacted by one of the authors (AS) who communicated directly with staff to obtain more information.

Data collection and analysis

Selection of studies: All titles and abstracts were screened independently by two members (AS and AP or AS and AO) of our team. The reviewers were not blind to the author or journal information. We obtained the full texts of manuscripts for all potentially eligible articles. Differences in selection of articles were discussed until consensus was reached. If the study eligibility could not be resolved via consensus, a third reviewer made the decision. The remaining eligible articles were included.

Quality review: No quality review was possible due to the lack of studies providing evidence based outcomes.

Results

The electronic database search yielded 1226 unique articles published between 1980 and July 2016 in English, Dutch or German. The search also revealed 207 reviews of which 32 had a relation to our research question. These 32 reviews revealed 17 relevant original articles which were missed during the search. These 17 were included in the reviewing process. This means that a total of 1243 articles were included in the review process. 37 articles were excluded for which no full text or abstract was available, 1032 were excluded based on title and abstract, 35 were excluded based on full text. Another 124 articles were excluded from the systematic review as not providing information on any structural or institutionalised healthcare facilities or programmes (e.g. local, limited in time initiatives carried out by individuals).

This left 15 articles that provided information on specialised healthcare facilities or programmes and these were included in the systematic review. See Figure 1 for the flow diagram of the search and Table 1 for detailed information concerning the included articles.

Table 2 gives an overview of the countries with known 2012-2016 available facilities or programmes to improve healthcare access for DHH individuals. The facilities have been categorised into four groups to facilitate description.

As the systematic review of the scientific literature provided insufficient information for our aim, we had to use additional data collection strategies. These yielded complementary information. We will present the integrated results of all strategies.

Table 1: Articles included in systematic review

Studies	Authors	Country of study	Year	Type of study
Special outpatient clinics for DHH patients	Fellinger et al[20]	Austria	2005	Descriptive
Specialised educational programmes for DHH patients	Kaskowitz et al[21]	USA	2006	Program evaluation
	Folkins et al[8]	USA	2005	Program evaluation
	Choe et al[22]	USA	2009	Program evaluation
	Jones et al[23]	USA	2005	Descriptive
	Jensen et al24	USA	2013	Program evaluation
	Hickey et al25	USA	2013	Program evaluation
	Harry et al[26]	USA	2012	Program evaluation
	Yao et al[27]	USA	2012	Program evaluation
	Sacks et al[28]	USA	2013	Program evaluation
Evaluation of effectiveness of SL interpreters in healthcare settings	MacKinney et al[29]	USA	1995	Case-cohort evaluation study
Evaluation of SL interpreters and SL training for professionals within maternity setting.	Equy et al[30]	France	2012	Descriptive
National (pilot) program to improve access, choice and control over maternity care	Sporek PE[31]	UK	2014	Descriptive
Training medical students	Thew et al[32]	USA	2012	Descriptive
Studies	**Authors**	**Country of study**	**Year**	**Type of study**
Healthcare Access Among Deaf People	Kuenburg et al[33]	Austria	2016	Review

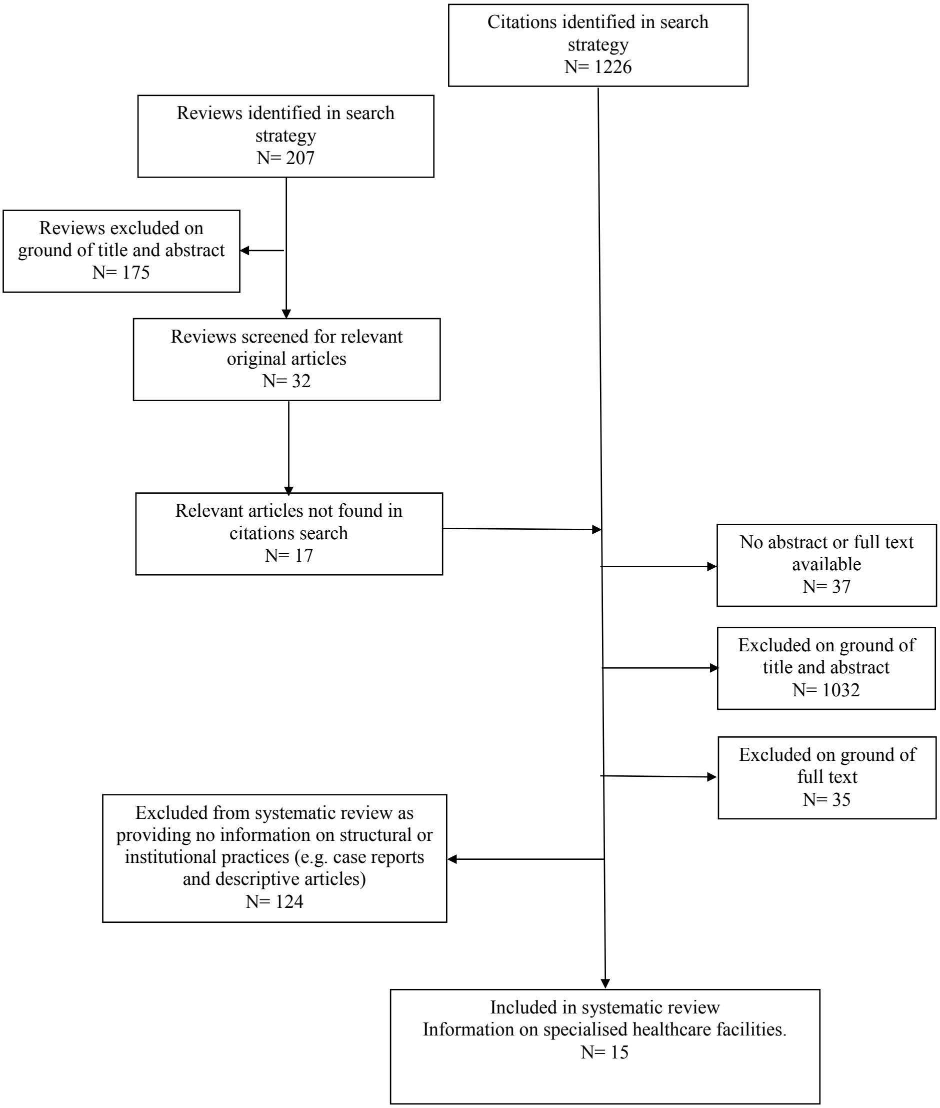


Figure 1: Flow diagram of literature search

Table 2: Overview of healthcare facilities for DHH.

	ICT facilities [34]	Qualified sign language interpreters [34-36]	General health facilities		Mental health facilities	
			Outpatient	Inpatient	Outpatient	Inpatient
Australia[37]	X	X	-	-	-	-
Austria	-	X	X	X	X	X
Belgium (Flanders)	-	X	-	-	X*	-
Brasil	-	X	-	-	-	-
Canada[38,39]	-	X	-	-	X*	X
Czech- Republic	-	X	-	-	-	-
Denmark	X	X	-	-	-	-
Estonia	-	X	-	-	-	-
Finland[40, 41]	X	X	-	-	X	-
France[42]	X	X	-	-	X*	-
Germany	-	X	-	-	X*	-
Hungary	-	X	-	-	-	-
Iceland	-	X	-	-	-	-
Ireland[43]	-	X	-	-	X	-
Israel	-	-	-	-	X	X
Italy	-	X	-	-	-	-
Japan[44]	X	X	X*	X	X	X
New Zealand[45]		X	-	-	-	-
Netherlands	-	X	-	-	X	X
Norway[46]	X	X	X*	-	X	-
Poland	-	X	-	-	-	-
Portugal	-	X	-	-	-	-
Qatar	-	X	-	-	-	-
Romania	-	X	-	-	-	-
South Africa	-	X	-	-	X*	-
Spain	X	X	-	-	X	-
Sweden[47]	X	X	-	X	X	-
Switzerland	-	X	X	X	X	X
Thailand [48]	-	X	-	-	-	-
United Kingdom	X	X	-	-	X	X
United States	X	X	-	-	X	X

Information gathered by personal contact with representatives in the individual countries. Countries not mentioned in this table have, to our knowledge, no structurally available specialized healthcare facilities for HI patients.

* Facility available only regionally.

Information and communications technology (ICT) facilities, face to face and remote sign language interpreting and translating facilities

We found 30 countries where it is possible for healthcare staff to contact a qualified sign language interpreter[36]. The standards for qualification differ worldwide. In this table we included countries where SL interpreters are certified, receive payment for their services and can be contacted through SL interpretation services, as listed in Table 2. Countries from which no recent information was available or where SL interpreters are available in only one city or region are not included in this list. Little information is available on how SL and speech-to-text interpreters, are trained to act in medical situations. Many countries reported that the number of interpreters is insufficient to provide a service in all required situations. To overcome the shortage of SL interpreters and/or to provide interpreting services in emergency situations, remote (online) interpreting facilities are available in Denmark, France, the United Kingdom (UK), Norway, Spain, Sweden, the USA, Australia, Finland and Japan. No studies on costs and/ or effectiveness are available[49]. One study investigated the effectiveness of the use of American Sign Language (ASL) interpreters in a primary care programme. DHH persons enrolled in this programme had easier access to ASL interpreters than the control group. The participants who used ASL in medical situations were more satisfied with physician communication and had some improved preventive care outcomes[29].

In the UK and Spain a medically orientated online translation database is available which healthcare workers can log into for support when faced with a DHH sign language user. In the UK this system was developed by a non-profit organisation called SignHealth which coordinates all specialised healthcare facilities for DHH people in the UK. SignHealth has connected a translation programme to a (remote) online interpreting system, which enables the caregivers to switch to online interpreting when communication using the translation programme alone is unsatisfactory. No international publications exist on the usefulness of these translation facilities. The British developers reported that it is a useful low budget system in situations where no sign interpreter is available. After the start of the programme, the use of live SL interpreters also increased. This was because users of the system reported that they preferred having a live interpreter present[50].

It is not known which countries provide speech-to-text interpreting for DHH people in medical settings. The extra time a healthcare employee needs to write or type information for a patient and the risk of loss of information might be overcome by the help of a speech-to-text interpreter. Several studies described the development of a system that shows speech captions on portable devices and micro displays, but its current accuracy is not yet satisfactory[51]. To our knowledge no experiments with telehealth (videoconferencing technology) have yet been reported in general medical settings even though several organisations are using this for mental healthcare provision. Studies on telehealth mental healthcare provision indicate that telehealth can be regarded as an efficient and cost-effective option for delivering healthcare to the DHH population[52,53].

Health promotion activities

We found 33 articles on health and healthcare knowledge and health promotion projects. 24 of these were excluded from the systematic review. Most focused on people who were DHH from a very young age and who have a SL as their primary language. Some focused on severe DHH in general. Some focused on improving the awareness of healthcare staff to the special needs of DHH patients.

Health related knowledge of DHH

One study[54] reported that 48% of the 166 participants had inadequate health literacy in comparison with a hearing control group. As the participants in this study had a higher educational attainment than is to be expected, the authors stated that the general prevalence of inadequate health literacy among people who are DHH from a young age is likely to be higher than that reported in this sample[54]. Other studies reported that DHH individuals have less cardiovascular health knowledge resulting in higher cardiovascular risk factors than the general population[6].

The great majority of articles published before 2010 concerned HIV/AIDS prevention. Studies describing knowledge concerning HIV and AIDS among severely DHH people reported a significantly lower level of knowledge about spreading and preventing it than among the hearing population[15,55]. Others stated that the HIV infection rate within the DHH population is expected to be much higher than in the hearing population[55,56].

Eight articles on knowledge about cancer prevention showed that DHH people have poorer knowledge concerning recommended interventions for cancer prevention. Australian and American studies on screening rates for breast, cervical and colorectal cancer showed overall screening rates comparable to the general population. However some DHH patients did not attend the recommended follow up[57,58]. Only one study showed lower screening rates. Orsi et al.[58] considered the utilization of invasive tests in the absence of knowledge regarding these tests “ethically worrisome”.

Interventions to improve health related knowledge in DHH

To improve knowledge concerning cancer prevention, two American groups developed and evaluated information videos in American Sign Language (topics: prostate and testicular cancer, skin cancer, ovarian cancer). After a single viewing of one of the videos, the knowledge of men and women participating in the study had increased significantly[24,25].

Because of the presumed increased risk of cardiovascular disease among DHH people an educational intervention train-the-trainer model was developed in Arizona, USA. This model was successfully rolled-out locally. Cardiovascular health knowledge increased, but whether this has resulted in a decrease of cardiovascular risk factors among the participants is yet to be evaluated[23.] Several studies mentioned small non-HIV related health education curricula and programmes for DHH people. Some of these involved education on general health and disease, others on sexual health, prevention of alcohol and/ or tobacco abuse or improvement of oral hygiene[59-62].

From our interviews we know that a much higher number of educational projects is started than is reported in the literature. It is highly probable that numerous small, local education projects have been initiated. To our knowledge hardly any websites or other multimedia carriers providing information on general health information for people with DHH are being developed. In the USA and Japan some local projects exist which focus on medical information in SL[23,24,63], but as far as we know such projects are not available on a national scale.

Interventions to improve the awareness and knowledge of healthcare staff concerning the special needs of DHH patients

One article described a training programme in Rochester, USA[32] for medical students to become more aware of the issues that arise when caring for patients with DHH. We know from the interviews that training is also available for some medical students in Northern Ireland, Ireland[64] and the Netherlands. These programmes do not have a structural character yet and their effect must be evaluated.

Specialised primary healthcare and health clinics

The UK and Norway reported having specialised general practitioners (GPs) with some SL skills and knowledge of the special health needs of DHH people. Staff of these facilities reported that they provide structural support by SL or speech-to-text interpreters during regular working hours. These facilities are embedded within a clinic which also provides other primary care facilities such as physiotherapy, social work and midwifery. No research papers were found describing these facilities and their effectiveness. In some regions of the UK a specialised maternity care programme is available to improve access, choice and control over maternity care[31,65].

Specialised secondary healthcare, outpatient clinics

Austria, Switzerland, Japan and France provide special outpatient clinics for DHH patients (Table 2). The first three countries mainly focused on providing healthcare in their special outpatient clinic itself. France mainly focused on supporting the communication of non-specialised healthcare staff in other (in/ out-)patient clinics. All these facilities also provide support to the medical staff involved when DHH patients are hospitalised in their hospitals (inpatient facilities). In Austria, France and Switzerland these facilities are supported through public financing. Experts and patient groups reported a higher perceived quality of healthcare and quality of health education within these specialised clinics[20]. There are no scientific studies to support these findings.

Discussion

It is difficult to get a clear view of special healthcare facilities globally available for people who are severely DHH. Availability of facilities changes and updated information is not easily retrieved. The information gathered from the systematic literature review, internet searches and interviews with workers in the field shows that while many countries attempt to improve facilities and communication with people who are DHH, the coverage is still poor and patchy. Even when facilities exist these have not been evaluated. Though the provision of specialised healthcare facilities for DHH individuals is quite haphazard, there seems to be a pattern in the order of facilities emerging in countries. Externalising behaviour, being problematic for society, seems to be dealt with first, resulting in specialised mental healthcare facilities[66,67]. Relatively cheap and easy to implement facilities such as ICT facilities and the use of available SL interpreters in medical settings follow. Only when enough DHH people live within a certain region (usually larger cities or urban areas), when there is a high level of awareness of the special needs of DHH and when sufficient finance is available, is it possible for specialised general health facilities to emerge and succeed. Due to communication barriers, DHH people are easily overlooked and lag behind in political discussions[68]. Therefore an important factor for successful healthcare provision to DHH people is the presence of enough DHH-aware pioneers and advocates who are able to mobilize and motivate healthcare providers, managers and politicians continuously.

Many ICT and telecom facilities are available, but few are used to assist DHH people in medical settings. Our informants reported that medical practice centres, hospitals and emergency services often cannot be reached by email or text message by DHH patients. Remote interpreter facilities were structurally used in only ten countries. In 30 countries (Table 2) SL interpreters are officially trained. However, the availability of SL interpreters does not necessarily mean that they are actually used in medical settings. Most of our informants reported a shortage of SL interpreters in their country. Countries that provide SL interpreters, do not always have SL interpretation available in acute situations. When these facilities are available, healthcare staff are, according to our informants, often not acquainted with them. This leads to underutilisation.

It is known that the use of interpreters in medical settings is cost effective[69]. No costs-benefits analyses are available on remote interpreting facilities. Costs are lower than when a live interpreter is used, however a remote interpreter is not identical to the presence of a live interpreter[49]. Currently it seems that remote interpreting is mainly used when no interpreter would otherwise be used, e.g. emergency situations or situations that are considered to be too short or not important enough to bring in an interpreter. The use of remote interpreting is expected to grow in the coming years, so more research into this subject is needed.

We expect that most countries providing official SL interpreting facilities also provide speech-to-text interpreting, but there is no registration of this. Although many DHH may benefit from the presence of a speech-to-text interpreter, the existence and merit of this service is even less well known than that of SL interpreting. It appears to be scarcely used in medical settings. Currently remote interpreting and online translation programmes are ICT facilities that support communication with SL users but in the future computerised interpreting may also become available. SignSpeak was a European project which aimed to develop a new vision-based technology for translating SL utterances into written text, in order to provide new e-services for DHH and to improve communication between hearing and DHH people, but other groups are also working on computerised interpreting.

All retrieved studies and all interviewed patient groups and experts described a lower level of health related knowledge among DHH persons. Several studies supported the hypothesis of patient groups that the information needs of DHH are not met during medical consultations[13]. Instead of providing more information to compensate for their pre-existing lower knowledge level, DHH people are often given even less information and explanations than hearing patients. Many projects have been undertaken to improve this knowledge level. Although two of these interventions were effective, the authors reported that more research is needed to determine what is the best and most cost-effective way to increase health related knowledge in this population[70]. To our knowledge, structurally available specialised health education is provided only by special schools for DHH children and youth. Due to the high percentages of sexual abuse of DHH children, many schools have special programmes on sexual education. Up to now no reports of a change in abuse rates after introduction of these programmes are available.

Many facilities that aim to improve the health knowledge of DHH people are not structurally available on national scales but only temporarily for the duration of a project or only for a small group of DHH people. Current developments in technologies such as the wide availability of internet, offer opportunities to improve health knowledge of DHH people. Some preliminary studies exploring these opportunities are beginning to appear, e.g. from Kushalnager et al., who were the first to evaluate the accessibility and usability of some health websites for American SL users[71].

The lack of structurally available programmes to improve health knowledge gives rise to ethical debates. Some authors discuss whether it is ethical to perform preventive medical tests when the patient's knowledge about these tests is poor, due to lack of information[58]. This discussion is probably also applicable to diagnostic testing and therapies.

Strength and limitations

This study provides the first overview of types of specialised health facilities that are available for DHH people and where they are available. Despite the many methodological issues, we think that an overview as presented in this article is essential for the development of DHH general healthcare provision.

The most important limitation is that many of the facilities have not (yet) been reported in the scientific literature; to enable this inventory of available facilities we had to mainly rely on grey literature. Most facilities do not have scientific studies to evaluate their effectiveness, so also the body of evidence to support these specialised facilities is extremely low. It was difficult to find information on facilities in some countries in the Middle-East, Russia, China and other parts of Asia. Since availability of facilities changes and updated information is not easily retrieved, some of the information may be outdated already.

We have used a combination of information sources to find and describe as many available facilities as possible, without this, more information would have been missed. But this also poses another methodological limitation. The internet searches do not provide permanent information, new information becomes available almost daily. Many of the websites we visited are updated regularly, or taken down, so information from these sources cannot always be retrieved. Every time that an internet search is repeated, other websites will be available and will have to be searched.

Implications for practice

Health and mental health are linked. Inadequate public health services for deaf people may have emotional and psychological mental health consequences for deaf people and inadequate mental health services may influence physical health. Therefore the issue of provision of support for deaf people in both mental health and public health settings is an important one. The information on where and what type of specialised healthcare facilities are available and how these facilities emerged can support healthcare workers who want to start a similar initiative. It enables healthcare workers from different countries to contact each other and learn from each other. Without any evidence of the effectivity of these facilities, it is hard to make them sustainable.

Implications for future research

There is a huge need for evidence-based evaluation of existing specialised mental and general healthcare facilities for DHH. Studies to evaluate their effect, costs and benefits are needed.

Conclusion:

Different (combinations of) facilities are used in different countries to attempt to meet the needs of deaf and severely DHH patients. Although several countries have some facilities to improve medical access for DHH patients, these are rarely reported in the scientific literature. No studies on the costs and or effectiveness of these facilities exist.

The quality of healthcare and health education for DHH people, especially for sign language users, is low compared to that for the hearing population. Experts and patient groups have reported a higher perceived quality of healthcare and higher perceived quality of health education in specialised healthcare settings. There are no scientific studies available to support these statements. Specialised healthcare facilities for DHH patients need to be further developed to respect their human rights and comply with medical ethical standards. This should be accompanied by high quality studies on the effectiveness of existing and new facilities. An important factor for successful healthcare provision to DHH people is the presence of enough DHH-aware pioneers and advocates who are able to continuously mobilize and motivate healthcare providers, managers and politicians.

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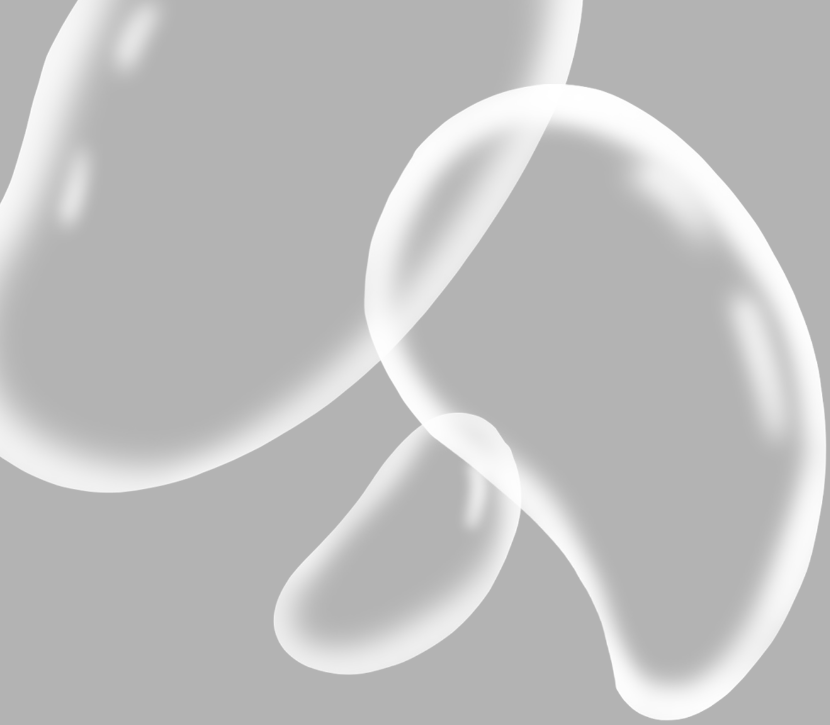

5.2

Specialized outpatient clinic for deaf and hard of hearing patients in the Netherlands: Lessons learned in an attempt to improve healthcare

Submitted article:

Smeijers AS, van den Bogaerde B, Ens-Dokkum MH, Oudesluys-Murphy AM. Specialized outpatient clinic for deaf and hard of hearing patients in the Netherlands: Lessons learned in an attempt to improve healthcare. Submitted Journal of Evaluation in Clinical Practice

Abstract

In 2013 a group of organizations and individuals in the Netherlands got together to attempt to improve access to healthcare and health education for deaf and hard of hearing (DHH) patients in the country. The result was the start of a specialized outpatient clinic named PoliDOSH. An independent research group was set up to evaluate the effect of this specialized clinic. Even though the initiative did not succeed and was closed after only two years, an extensive analysis of the start-up and functioning of the whole process was made. The findings are reported in this paper and advice concerning setting up a similar facility in the future in the Netherlands or elsewhere is given.

Data collection: structured and non-structured questionnaires and structured interviews.

Outcomes: Only a small group of DHH patients indicated that they felt a need for consultations at the PoliDOSH. However, to ensure that DHH patients are provided with the opportunity to access optimal medical care it is essential that the possibility to visit specialized healthcare facilities exists. There is a great need for facilities to collect and disseminate information to and about DHH patients. The information should be aimed at providing psycho-education for 1) the DHH persons themselves and 2) healthcare professionals, concerning the specific needs and problems of this patient group. To ensure successful functioning of a specialized facility the **team members should include a representative group of DHH members.** All key functions should be filled by top experts in the relevant fields as well as an expert in communication and needs of the target group. It is essential that regular healthcare workers who look after the target group are frequently informed about the existence and possibilities of these facilities.

Thorough market research prior to start up is needed to enable the facility to connect with the needs of patients. The start-up period should allow sufficient time for the project to become known and for patients to become familiar with it and trust it**.** Charting the availability of medical and paramedical care available for DHH people in the whole country can help to concentrate the care in various regions and strengthen the already present expertise.

Introduction

Ideally a healthcare system should be easily available to all who need it. However, Deaf and Hard of Hearing (DHH) patients often report that they experience feelings of fear, mistrust and frustration during contact with healthcare professionals (Barnett & Franks, 2002; Steinberg, Barnett, Meador, Wiggins, & Zazove, 2006; "United States District Court Georgia. Sign language interpreters: US court says hospital discriminated against deaf patient," 2008). They feel that physicians do not understand them (Bat-Chava, Martin, & Kosciw, 2005; McEwen & Anton-Culver, 1988; Schein & Delk, 1980). Good communication with DHH patients is essential because poor communication may lead to wrong diagnoses and misguided therapy (Hochman, 2000; "US Department of Justice: Communicating with people who are deaf or hard of hearing in hospital setting," 2015; Woodroffe, Gorenflo, Meador, & Zazove, 1998; Zazove et al., 1993). It has been shown that many physicians are not sufficiently trained for caring for DHH patients, since academic curricula do not provide the necessary skills to meet the needs of this population (Barnett & Franks, 2002). However, various services and technical support systems have been developed to attempt to improve access to medical care for these patients.

There are several reasons why DHH patients' access to healthcare facilities is difficult (Arulogun, Titiloye, Afolabi, Oyewole, & Nwaorgu, 2013; Barnett & Franks, 2002; Bentes, Vidal, & Maia, 2011; Royal Institue for Deaf People, 2004; Folkins et al., 2005; Hochman, 2000; Jones, Renger, & Firestone, 2005; Kritzinger, Schneider, Swartz, & Braathen, 2014; Maddalena, O'Shea, & Murphy, 2012; Parsons, 2013; Peinkofer, 1994; Pereira & Fortes, 2010; Steinberg, Wiggins, Barmada, & Sullivan, 2002; Tedesco & Junges, 2013; Ubido, Huntington, & Warburton, 2002; Zazove et al., 1993). Communication is the greatest barrier, as availability and use of sign language (SL) mediation by interpreters is restricted and medical information in SL is scarce in many countries (Folkins et al., 2005; Kritzinger et al., 2014). The problem is compounded by the fact that DHH adults have inadequate access to information about health and healthcare and also have less knowledge of these subjects than what is generally considered by others to be common knowledge (Barnett, 1999; Jones et al., 2005; Kleinig & Mohay, 1990; McKee, Paasche-Orlow, & et all., 2015; Pfeinkofer, 1994; Smith, 2014; Vernon & Andrews, 1990). The reasons for this include restricted exposure to many topics during the education of DHH children (Tamaskar et al., 2000) and the fact that most DHH people do not have access to 'ambient information' because they do not overhear conversations or hear radio and television announcements (Barnett, 1999; Jones et al., 2005; Tamaskar et al., 2000). Moreover, low literacy is also a factor and means that information from newspapers, magazines and television captioning is less accessible to them than it is to hearing people (Easterbrooks & Beal-Alvarez, 2012; Napier & Kidd, 2013; Vernon & Andrews, 1990).

Access to healthcare for DHH patients is a worldwide problem and only a few centers have paid specific attention to this. In the Netherlands there is a good network of specialized facilities for mental healthcare for DHH people but none for general practitioner facilities and physical health problems. It was only on June 14th 2016 that the Dutch government signed the United Nations' convention agreement on the rights of persons with a disability which should ensure that special attention should be given to sign language and the rights of DHH people in the Netherlands. Up to then there was no legislation on the rights of persons who were DHH other than that stated in the laws on general equal rights for all. Most general information, also that concerning health and healthcare, is available to DHH people in only a very limited manner. Sign language interpreters or sign-to-text services are commonly not used in medical consultations.

In view of these problems a group of interested organizations and individuals in the Netherlands got together to attempt to improve access to healthcare and health education for DHH patients in the country. The result was a plan to start a specialized outpatient clinic for deaf and hard of hearing patients in the Netherlands which would address many of these problems. This paper describes this endeavor and the lessons learned from it.

PoliDOSH initiative

A plan for a specialized outpatients' clinic for DHH patients (acronym PoliDOSH) was conceived by staff members (with normal hearing) of Royal Dutch Kentalis (Kentalis, 2017). This is a national organization specialized in providing diagnostic, educational and care services to people who are deaf, hard of hearing or deafblind, as well as to people with severe speech/language impairment or autistic spectrum disorders accompanied by severe speech and language difficulties. These hearing professionals decided, both on the grounds of signals from their own practices and research on DHH health issues, that medical care for these patients needed to be improved. The organization of PoliDOSH mirrors that of the specialized outpatient clinics for DHH patients in Austria[1]. Its main purpose was to provide a safety net for patients who, for one reason or another, did not receive adequate appropriate medical care in the regular healthcare system. It aimed to cater primarily to adults with mild to severe hearing loss and an average IQ (>80).

Process

In September 2013 a project proposal was written by a group of hearing individuals, consisting of a physician, project leader and secretary. They contacted various organizations involved in the care of DHH people at the end of 2013. After this the project group was extended by also including DHH members. The official project group was installed on 28

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[1] (http://www.barmherzige-brueder.at/pages/issn/gesundheitszentrumgehoerl).

January 2014. PoliDOSH was officially opened on World Deaf Day, 27 September 2014. PoliDOSH was set up as a primary care facility, located within a local general hospital. The medical team consisted of one physician (hearing, non-signing, specialized in treating patients with multiple disabilities) and one nurse (suddenly deafened, signing), they were supported by an NGT[2] interpreter (hearing). Consultations were preferably on Friday morning. Consultation fees were covered by all health insurance companies.

The project was planned to be set up for a minimum of 3 years. However, at the beginning of 2016 it became clear that the outpatients' clinic did not attract a sufficient number of patients to be able to evaluate this initiative according to the analysis plan which had been drawn up at the outset. During the 19 months of operation only 23 patients had attended this outpatient facility.

During the preparation of the PoliDOSH it was clear that this new facility would need to be monitored and evaluated. An external independent group (including the authors of this paper) was asked to evaluate the effect of this specialized clinic and a model for evaluation was drawn up. Even though the initiative did not succeed and was closed after only two years the evaluation group carried out an extensive analysis of the start-up and functioning of the whole process. The findings are reported in this paper and advice concerning setting up a similar facility in the future in the Netherlands or elsewhere is given.

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[2] NGT (Nederlandse Gebarentaal) means Sign Language of the Netherlands.

Methods

Data collected in three different manners were used to evaluate how the PoliDOSH functioned.

A questionnaire was completed by PoliDOSH patients (2.1)

- Structured interviews were carried out with professionals of the PoliDOSH and those directly concerned with its running (2.2)
- A questionnaire for members of the Deaf community was made available online (2.3).

Questionnaire completed by PoliDOSH patients

All patients who attended the PoliDOSH were asked to complete a questionnaire. This questionnaire included questions on gender and age of the patient, five questions on the referral process and reception at the PoliDOSH, six questions on communication with the physician at the PoliDOSH, seven questions on the content of the consultation and three questions on their general experience with the PoliDOSH. The questionnaire was completed online using Unipark software (Unipark, 2015). The questionnaire can be obtained from the corresponding author. The questions were presented in Sign language of the Netherlands (NGT) and in written Dutch. The secretary of the PoliDOSH sent the invitations to take part in this evaluation, the results were returned directly to the investigator through Unipark allowing these to be analyzed anonymously without the personnel of the PoliDOSH seeing them. The invitations were sent after the patient had attended the PoliDOSH three times, or when consultations ended.

Structured interviews

Ten structured interviews were carried out concerning the start of the PoliDOSH and how it functioned. Eight structured interviews were carried out with personnel of the PoliDOSH and members of the project group. They consisted of one physician (hearing) one nurse (suddenly deafened), one NGT interpreter (hearing) two secretaries (one deaf and one hearing), one project leader (hearing), two advisors (both deaf, one of whom was previously a board member of Dovenschap)[3].

Three structured interviews were carried out with people who represent interest groups, one sitting board member of Dovenschap[3] (deaf), one ex-board member of Dovenschap (deaf with a double role as this person was also an advisor for PoliDOSH) and one member of the mill organization[4] (hearing).

Eight to 11 open questions were posed in the structured interviews. These concerned the way in which representatives of organizations and personnel were involved in the setting-up and the organization of the PoliDOSH, what their experience was, how they estimated the need for a special PoliDOSH, what they considered as strengths and difficulties and their suggestions for how the PoliDOSH could be improved. The questions are available from the corresponding author.

Questionnaire Deaf community

A short questionnaire was developed in both NGT and written Dutch, based on information from the structured interviews (2.2) and anecdotal information gained from conversations with visitors of the Amsterdam Foundation for the Wellbeing of the Deaf (AKA the Deafclub in Amsterdam). This questionnaire contained 10 questions concerning awareness of the PoliDOSH and the need for this or other types of specialized healthcare (questionnaire available from the corresponding author). The questionnaire was completed online using Unipark software. It was distributed by 14 clubs and organizations for Deaf people in the Netherlands, support organizations, Facebook pages of a Deaf Gain meeting group and the investigators.

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[3] Dovenschap is the largest independent interest group for Deaf people in the Netherlands.

[4] The mill organization is a collaboration of 7 interest groups/ patient organizations in the Netherlands.

Results

The results will be discussed per dataset.

Questionnaire completed by PoliDOSH patients

Twenty-three patients made use of the PoliDOSH. After attending, the questionnaire was completed by 12 patients (52%). Nine patients stated that they found communication with the physician good, one moderately good, no one replied that they considered communication fair or bad and two patients did not answer this question.

Table 1: Communication with the PoliDOSH physician

	Good	Moderate	Fair	Bad	Not answered
How was the communication with the PoliDOSH physician?	9	1	0	0	2

Six patients stated that they were happy with the PoliDOSH, one patient was moderately happy and five patients did not fill out this question.

Table 2: Degree of satisfaction with PoliDOSH

	Yes	Partly	No	Not answered
Do you find PoliDOSH satisfactory?	6	1	0	5

Ten patients indicated that they found that the referral process proceeded smoothly, two patients did not answer this question. No patients offered suggestions for improvement. Statistical analysis or comparative evaluations were not possible in view of the very small number of respondents

Results of structured interviews

Ten structured interviews were conducted concerning the start-up of PoliDOSH and how it functioned. In the text giving the results, the number of respondents who gave a certain answer is given between brackets and quotes and answers of the interviewees are placed between inverted commas.

Involvement in setting up PoliDOSH

One representative of the mill organizations was indirectly involved in setting up the PoliDOSH. He was not involved with the content before the decision was made to start this initiative, but he functioned as a contact person between PoliDOSH and the various interest support organizations when PoliDOSH became a reality. He provided advice on practical matters such as identifying the target group, approaching patients and reaching interest groups.

Representatives of the support group Dovenschap indicated that they were not involved before the decision had been reached to set up PoliDOSH, but there was some contact after it had started. Dovenschap stated that deaf and hard of hearing individuals mainly experienced communication problems in accessing medical care. They stated that these problems could be solved by providing NGT interpreters or speech to text interpreters. They preferred to concentrate on aiming for the achievement of nationwide availability of interpreters rather than providing specialized medical facilities.

Need for the outpatients' clinic facility

All the PoliDOSH personnel members indicated that they would not personally seek medical care at a facility like PoliDOSH. Two stated that they would attend the PoliDOSH only if they had attended several other physicians without their problems being resolved. The reason they gave was that they thought that the professionals working at PoliDOSH would spend more time and would explain things better than other physicians. The remaining members stated that they did not need a facility such as PoliDOSH because they were able to communicate well, or if necessary, they would take an interpreter with them to medical appointments. They also added that they were highly educated and assertive enough to ask relevant questions that other patients might not dare to ask.

The personnel members of the PoliDOSH and representatives of interest groups indicated that they knew some people in their surroundings who might probably need facilities such as PoliDOSH. These people were less well educated (3) or less assertive (3). They also thought that these people would be difficult for the PoliDOSH medical team to reach because they were usually less active in interest organizations (2) and more time would be necessary to win their trust. They stated 'the step to attend the PoliDOSH involves changing old habits and this takes a long time' (6).

Description of the target group

All people who were DHH were officially regarded as the target group at the set-up of the PoliDOSH. Various answers were given to the question of who, in practice, should be regarded as the main target group of PoliDOSH. These answers included 'all deaf and hard of hearing persons', 'all deaf people except those who suddenly lost their hearing as adults', 'elderly deaf and severely hard of hearing persons', 'poorly educated deaf persons'. Almost all the participants gave different answers ranging from 'all deaf and hard of hearing people without regard to their age or educational level' to 'only specific subgroups'.

Strengths of PoliDOSH

Personnel indicated that, in their view, even though the aim of PoliDOSH had not been reached, the project clearly had not failed**.** Thanks to the project, some medical information is now available in NGT and a general practice-based nurse specialist especially for DHH patients has been appointed at a general practice in the vicinity of the Gelderhorst, which is the only center in the Netherlands for elderly deaf people. In addition, four personnel members stated that they had learned a lot as a team and that the project had contributed to their personal development.

Team. When asked what went well in the PoliDOSH project, all eight personnel members mentioned the cooperation within the team as the first point. All stated that they had formed a good, close group with team spirit, trust in each other and they had worked well together. The majority of them also indicated that this had not been the case at the beginning. At first it had been seen as a project where 'the hearing were trying to do something good for the deaf' (3). Hearing members had to get used to the working style of deaf members (3), and hearing members had first to gain the trust of the deaf members (5). It is striking that the hearing members experienced the project as containing relatively more 'conflict' while the deaf members found that they 'had had a good discussion'.

The team gradually became more acquainted with the specific (Deaf cultural) aspects of the target group, which led to better communication and information. Examples of this were that information meetings and information folders which were originally organized and written by hearing members were later revised by deaf members who made the language and the information clearer and more succinct (4). Two members emphasized the importance of using a deaf photographer and a deaf website builder, both of whom ensured that the provided information suited the target group better.

Preparation. The three original members of PoliDOSH admitted that the amount of preparation necessary for setting up such an outpatients' facility had been greatly underestimated. Delaying the planned opening date by 10 months ensured that it was properly prepared to start (2).

Points for improvement of PoliDOSH

The representatives of interest organizations and PoliDOSH personnel offered several possible reasons to account for the fact that POLIDOSH attracted so few patients.

Vicinity of care.

Medical care in the Netherlands is organized in such a manner that almost everyone has one or more general practitioner (GP) practices within walking distance of their home. Inhabitants of the Netherlands are used to not having to travel very far to a hospital either, with most people having a hospital within a radius of 5 km of their home (CBS, 2009). However, almost all patients had to undertake a longer journey to attend PoliDOSH. The interest group representatives and seven personnel members indicated that DHH patients with an average to high education level prefer to access medical care near their home. Even though the representatives of interest organizations stated that their clients regularly encounter communication problems when attending the general practitioner or medical specialist in their area, 'they suppose they will go home with the correct medication'. The three representatives of the interest groups stated that poorly educated DHH persons or DHH persons with other disabilities probably need the specialized care provided by PoliDOSH, but these groups would find it difficult to access this as they generally do not have personal transport and find public transport too expensive. Six personnel members indicated that the location of PoliDOSH was not sited centrally enough in the Netherlands and that the location was difficult to reach by public transport. Two personnel members said that patients were regularly unable to attend before 11 am due to the long distances; patients who came by car did not want to get caught in rush hour traffic and those who came by public transport travelled only in the hours when the prices of travel tickets were reduced outside the rush hours. Personnel gave various arguments for their opinion that it was undesirable to hold the consultations only on Fridays. This was not mentioned by patients. Several personnel members indicated that they considered the travel time to the PoliDOSH too long for some (potential) patients but their views about an acceptable journey time ranged widely.

Three points were proposed for possible improvements:

1) A more central location in the country, easily accessible by public transport (2).
2) Hold the consultations in turn in four or five locations across the country so the travel time for patients is always less than 90 minutes (3).
3) Have a 'mobile' outpatients' facility in a bus or a van so consultations can be carried out all over the country (4).

Duration of the project. Six respondents found that the three year duration of the project was too short to get such a facility set up and running well and that at least twice as much time would be necessary to achieve this. They gave several possible reasons for this. Firstly, a process of consciousness arousal of DHH people is necessary to allow them to become aware of their own higher risk of health problems. This process takes time. Secondly, the deep seated mistrust of some DHH patients towards the medical and paramedical professions means that it will take time to win their trust. Thirdly, there was no previous experience in the Netherlands with setting up a similar project for DHH patients. The personnel admitted that they later became aware that they had underestimated the complexity and enormity of this project (3).

Communication with the target group. A few of the hearing personnel members stated that it was ‘only after the first contacts with e.g. the mill organizations that it became clear that the target group (all deaf and hard of hearing people) was comprised of very diverse subgroups depending on the hearing status, background and age’ (2). Many personnel members and representatives of interest groups stated that the individual subgroups within the target group should receive more attention and there should be a designated policy for each subgroup. They remarked ‘this makes it more complex but is essential if these subgroups are to be reached’. (5)

More emphasis on health promotion. Before DHH people are prepared to attend a specialized outpatients’ clinic or take other steps to improve their health, they must first gain insight into the possibility that their health may be poor or under threat and understand the possible reasons for this (4). The team members had been chosen because of their competency to set up and run a specialized facility. They were not experts in the fields of health promotion/ health communication for DHH people and social media (1). The amount of health information available on the PoliDOSH website[5] is still too limited, more information is necessary (2).

Team. Three of the interviewees indicated that it would be better if there were more DHH team members, which would create a better representation of the different target group in the team. It would also have been better if DHH team members had been involved at an earlier stage of the project. They advised that the initiative for starting a similar project should be taken by DHH people themselves.

Small close knit. Dovenschap indicated that the Deaf community in the Netherlands is small and ’there is a lot of gossip’. Even relatively minor news is generally rapidly spread by WhatsApp and Skype. DHH patients dread meeting acquaintances in the waiting room of a specialized outpatients’ facility because, within a few hours, it may be broadcast on social media and their friends and many acquaintances will know that they have attended the facility. The risk of running into DHH acquaintances is much less when they attend the local general practitioner who usually has only one or two DHH patients in the practice.

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[5] http://polidosh.nl

The role of Royal Dutch Kentalis.

The original initiative for setting up the PoliDOSH was taken by Royal Dutch Kentalis. The representatives of interest organizations and two personnel members stressed that this organization is regarded by DHH people as caring for them ‘from the cradle to the grave’, because they are dependent on Kentalis from a very young age. At the start of PoliDOSH there was some resistance to the fact that this facility was also coming from Kentalis. Patient information is sometimes exchanged between various departments of Kentalis and because of this some DHH people were apprehensive about the possibility that their medical information could be made available to more organizations connected to Kentalis. They worried that their medical information might not be safe at PoliDOSH.

Evaluation of the online questionnaire among the Deaf community

The group of patients that PoliDOSH did actually reach was people who are deaf from the prelingual period. Therefore, the questionnaire to evaluate functioning of PoliDOSH was specifically aimed at this target group. A total of 36 respondents completed the questionnaire. Of these, 30 reported that they were deaf, one hard of hearing and five that they were hearing. The questionnaires of the hearing respondents were excluded. The remaining 31 respondents included 10 men and 20 women and one respondent did not answer the question on gender. The age of the respondents was relatively older, with a mean age of 58 years (range 23-77 years).

Twenty-two respondents stated that they were aware of the presence of PoliDOSH and three had visited it (Table 4). These three patients had been satisfied with the care they received. Two-thirds of the respondents stated that they would certainly, or possibly, attend the PoliDOSH should they have physical complaints in the future. The reason they gave was that they expected that they could communicate better with the PoliDOSH physician than with their own physician and/or that they would receive more information there. One respondent indicated that he would attend the PoliDOSH only if a second opinion was needed (Table 6). One-third of the respondents indicated that they would certainly not attend the PoliDOSH. The reason most often given for this was the long distance or travel time. Four respondents gave various reasons why they (as yet) had no faith in the PoliDOSH (Table 7).

Table 3: Awareness of PoliDOSH.

	Yes	No	Not answered
Do you know PoliDOSH exists?	22	9	0

Table 4: Attendance PoliDOSH

	Yes	No	Not answered
Have you attended PoliDOSH?	3	19	0

Table 5: Willingness to attend PoliDOSH

	Yes	No	Maybe	Not answered
Would you attend PoliDOSH if you had physical complaints?	3	11	14	3

Table 6: Reasons given for being prepared to visit PoliDOSH if one has physical complaints

Reason	**Number of times given**
Good communication	4
Second opinion	1

Table 7: reasons given for not wanting to attend PoliDOSH in the presence of physical complaints.

Reason	**Number of times given**
Too far away	11
Preference for own general practitioner or hospital specialist	5
Too little information about PoliDOSH, possibly later when PoliDOSH is better known	3
Aversion to institutions connected with Royal Dutch Kentalis, because of fears concerning confidentiality of medical information	1

Discussion

The plan to set up a special outpatients' clinic in the Netherlands to provide primary healthcare for DHH people with somatic disorders was conceived and executed with great care. It was not foreseen that there would be only limited interest in using these facilities. The analyses of the information gained during evaluation of the process provided some interesting information. On analyzing the results of the structured interviews and the online questionnaire it was striking that some points turned up regularly. Some of these will be discussed here.

Distance to care

Almost all the respondents and some of the DHH interviewees indicated that they considered they would need specialized care only when they felt the need for a second opinion or if the regular medical healthcare system did not succeed in solving their problems. Therefore, it is to be expected that the number of patients who would attend the PoliDOSH would remain limited. However, the interviewees and respondents emphasized that they found it important that such a facility existed.

All the patients who attended PoliDOSH stated that they were happy with the offered care but there were too few answers to be able to draw conclusions. It is important to DHH persons that, just like hearing persons, they are able to receive good medical care without having to travel long distances and this must be taken into account in the future. In the Netherlands only groups with specific care needs seem to be prepared to travel long distances for this care. An example of this are deaf persons with psychiatric problems who did not receive satisfactory care within the regular medical system. They are willing to travel to specialized centers for mental healthcare provision for DHH. Another example is elderly Dutch Deaf people who are willing to move to a specialized center for the elderly, known as 'de Gelderhorst'.

A national specialized center could play an important role in centralizing care and providing information facilities and supporting second opinion consultations. There does not appear to be sufficient need for a specialized outpatients' clinic for primary care for DHH persons in the Netherlands. Throughout the Netherlands there are many individual healthcare providers experienced in caring for DHH patients. These include general practitioners, psychiatrists, physiotherapists, dieticians, psychologists etc. There is no national directory of these healthcare providers, but it could be helpful to compile an overview so that the care for DHH people can be concentrated within different regions and the existing network of care providers strengthened. This network could then be used by DHH people after attending a national centralized specialized facility.

Diversity of the target group.

The target group of DHH persons included a great number of subgroups, each with its own needs. These included persons who are deaf from the pre-lingual period, persons who became deaf at a later age, those with sudden hearing loss, persons with and persons without a cochlear implant and persons who are severely hard of hearing. All these groups have their own communication needs. PoliDOSH mainly reached the prelingually deaf group. If the other subgroups are to become interested in a facility such as PoliDOSH, it is imperative that their communication needs are investigated and met.

One example of differences between sub-groups is that severely hard of hearing persons often do not use NGT but use the Dutch language with signs support, lip reading and /or subtitling. On the PoliDOSH website films were used with information in NGT and written text. This communication method is mainly aimed at prelingually deaf persons. Even though many hard of hearing persons will be able to access this information they will feel that it was not aimed primarily at them and they may lose interest. It is essential that communication is aimed specifically at each subgroup e.g. separate entry portals on the website for persons who are prelingually deaf, persons who became deaf later in life, and hard of hearing persons, as well as for the healthcare providers.

This study showed that preparation for PoliDOSH was not properly planned. Before or during the planning period for PoliDOSH no investigations were carried out to see if there was a need for such a specialized facility. Neither were the interest groups approached to ask what the needs of their target group were and to see whether the aims of PoliDOSH would tie in with their wishes. The inclusion of a contact person for all the mill organizations during the setting up of PoliDOSH was ‘too little and too late’ and therefore there was a lack of clarity about the interests of the various subgroups and insufficient involvement of the interest organizations. Support for PoliDOSH could possibly have been greater if the interest groups had been involved earlier and not only after the project was started.

Awareness of health problems

Many DHH people stated, in both the structured interviews and the online questionnaires, that they considered PoliDOSH a good initiative, but it was not for them. This was because they considered themselves able to communicate well, were well educated, assertive enough and therefore they expected that they would obtain good medical care without needing PoliDOSH. The statement ‘because the body of a deaf person is the same as the body of a hearing person, means I will get the correct tablets’ showed how DHH persons regarded the fact that they were deaf or hard of hearing not relevant and seemed unaware of the consequences this could have during a medical consultation. It did not occur to DHH people that a good reason to attend PoliDOSH would be to ensure that they were well informed about their medical condition and medication. This demonstrated the limited awareness of deaf and hard of hearing people of the fact that information is missed during a consultation.

On one occasion PoliDOSH organized a 'health fair' for deaf and hard of hearing persons with presentations, an information market and discussions about various health subjects (doof.nl, 2016). Many respondents indicated that they found the information meetings and this health fair very useful. The information on the website about frequently occurring disorders was also greatly appreciated. It is probable that this type of health information promotion and psycho-education could lead to more health gain in the short term than the consultative function of PoliDOSH.

Providing information for healthcare professionals

While PoliDOSH focused on promoting the clinic among potential patients, not much efforts were made to inform regular healthcare professionals about the existence of PoliDOSH. This lack of awareness among healthcare workers might exclude potential patients, i.e. DHH with low levels of education who live isolated from the Deaf community and the more highly educated DHH patients who stated they do not need PoliDOSH. Steps must be taken to reach these potential patients. This would probably need an intensive campaign, including presentations at conferences, writing and publishing articles in specialized scientific journals for medics and paramedics as well as hospital newsletters etc.. Interest organizations such as the Dutch organizations for general practitioners, medical specialists and physiotherapists, should be able to advise how their members are best reached.

It may be more effective to concentrate, in the first instance, on providing information for healthcare providers in the region where specialized services for DHH people are available or in regions where relatively more DHH people live.

Team

It is important that the key functions of PoliDOSH are filled by top experts and also include an expert from the target group. For example, when patient information aimed at NGT users is being developed this should be done by a combination of persons with experience in developing patient information and persons with experience with the specific needs of prelingually deaf people. It is essential that the target group is well represented in the team. Young et al. (Young AM, 2000) have stated that teams of service providers comprising deaf and hearing members face enormous challenges in developing effective working relations. These dynamics were also seen within the PoliDOSH team.

Conclusions

Only a small group of deaf and hard of hearing patients indicated that they felt a need for consultations at the PoliDOSH. However, to ensure that DHH patients are provided with the opportunity to access optimal medical care it is essential that the possibility exists to access a specialized healthcare facility, if desired or if necessary, or to provide an appropriate second opinion.

There is a great need for facilities to collect and disseminate information to and about DHH patients. The information should be aimed at providing psycho-education for 1) the DHH persons themselves and 2) the healthcare professionals concerning the specific needs and problems of this patient group.

Recommendations

Two categories of advice are given:

1) General advice for future international projects for improving medical care for DHH people
2) Advice concerning a restart of a DHH medical facility in the Netherlands.

General advice

- When a similar project is being considered it is essential for its success that this is supported by the target group itself, that the needs of the patients are fully assessed and the target group is fully represented in the team.
- This study showed that there is a need for more information concerning health and medical topics. This need may be filled by various means such as setting up a specialized center which produces and disseminates information which can be available online and organizes meetings and informal health information get together sessions.
- Charting the availability of medical and paramedical care available for DHH people in the whole country can help to concentrate the care in various regions and strengthen the already present expertise.
- Special attention must be paid to the specific communication needs and possible medical problems of DHH people during the training of healthcare workers.

Advice for a situation when PoliDOSH or a similar project would be restarted in the Netherlands

A mobile team should be formed, consisting of a physician, nurse and a team of interpreters, and should be available for consultations all over the country, in various locations such as the office of the patient’s own general practitioner.

- The start-up period should be sufficient to allow time for the project to become known and for patients to become familiar with it and trust it. It is estimated that it will cost 6-10 years for this to be achieved. No comparable data are available on the precise duration necessary for the start-up.
- All key functions should be filled by top experts in the relevant fields as well as an expert in communication and needs of the target group.
- It is essential that regular healthcare workers who look after the target group are comprehensively informed about these facilities.

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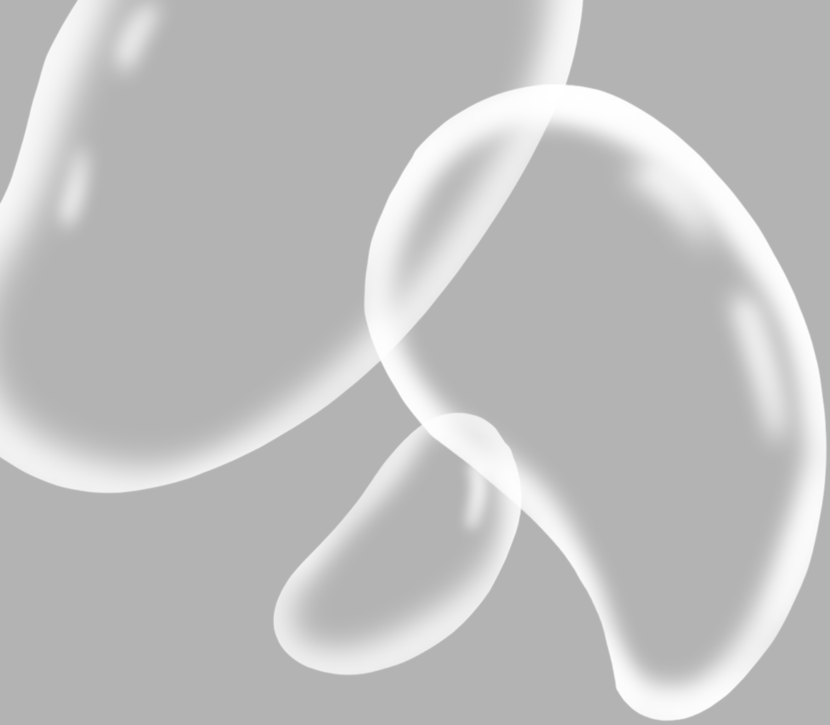

6

General discussion and conclusions

General discussion and conclusions

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.

Universal recommendations:

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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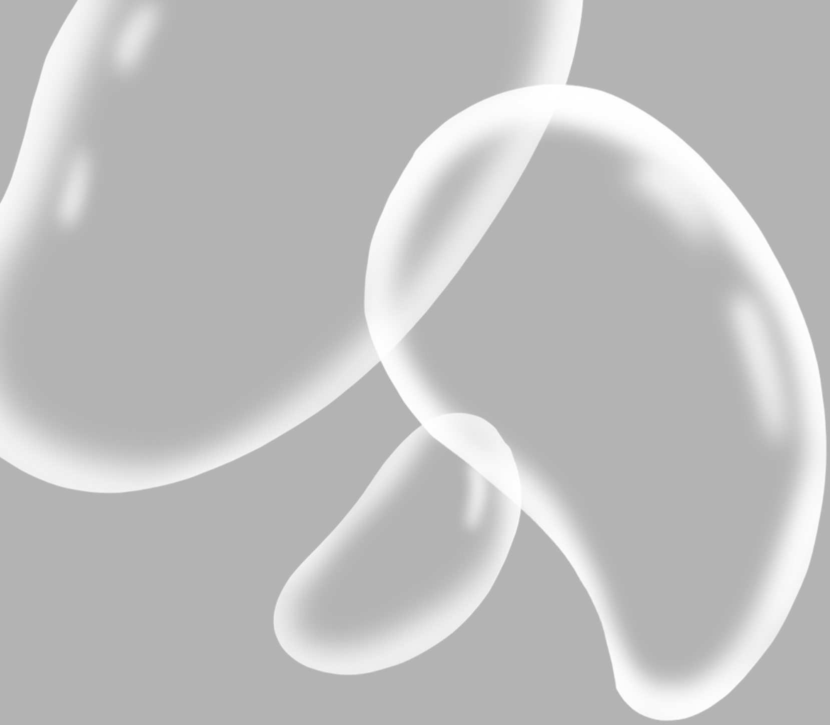
7

Summary



7.1

Summary

Summary

It is well documented that both ethnic/cultural differences as well as language differences complicate a satisfying and effective doctor-patient relationship. Although these ethnic/ cultural and language differences are also present during communication between Deaf patients and their hearing physicians, hardly any research has been done on this subject. The research described in this thesis tries to fill some of these gaps.

Hearing loss is not a rare disorder, approximately one child per 1000 is born deaf or severely hard of hearing. The number of people with hearing impairment increases with age to about 1.6 per 1000 in adolescents and to 88 per 1000 at the age of 65.

In order to distinguish between the clinical meaning of the term *deaf* and the cultural meaning of *Deaf*, we adopt the convention of referring to the latter with a capital *D*. When both deaf and hard of hearing people are addressed, the abbreviation DHH (Deaf and Hard of Hearing) is used.

Most healthcare workers are not aware of the specific issues they may encounter when caring for DHH patients. In contrast, DHH patients themselves report that they often experience barriers in healthcare.

Chapter 2 describes the communication challenges and medical, ethical and legal issues that a physician can face when caring for DHH children and children of DHH parents. Due to the communication barriers it is tempting to communicate primarily with the hearing child/ adult present and thereby exclude the DHH person. As a consequence, DHH children/ adolescents and/ or DHH parents may receive the necessary information not from their physician but from their hearing relative. It is up to the physician or healthcare worker to decide at what age and in which situations it is acceptable for parents or children to translate and when to bring in a professional interpreter. In order to obtain informed consent, it is almost always necessary to have a sign language or speech-to-text interpreter present. In all cases, but particularly in the case of DHH adolescents, privacy needs must be respected. DHH youngsters must be given the opportunity to communicate with their physician without parents being present.

In **Chapter 3** we describe the many methodological issues that we encountered in trying to obtain quantitative data from DHH participants, including sign language users. The lack of suitable instruments for sign language users poses enormous problems for scientific research. Quality of life research, health inventories and psychological testing is usually done through written questionnaires. From research in ethnic minority groups it

is known that standardized questionnaires can be used for people with a linguistic and cultural identity different from the original target group only after a meticulous process of translation and cultural adaptation. This is hardly ever done for Deaf sign language users, neither clinically nor in research settings. As far as we know, only one adapted and translated Health Related Quality of Life (HRQOL) questionnaire for Deaf sign language users exists, and this is in Austria, and we found no guidelines for translating and adapting questionnaires into sign language.

We attempted to overcome these difficulties by developing a standardized guideline for translating internationally used, written questionnaires into a sign language. The theoretical background, development and use of this guideline are described. This guideline is based on current guidelines for translating and adapting HRQOL questionnaires for spoken languages and adaptations were made based on experiments and expertise. We advise the use of carefully selected internationally validated written questionnaires in this population. If this is not done properly, bias will arise possibly resulting in many misdiagnoses. With this guideline we hope to raise awareness for possible bias in testing sign language users and to set a standard for practitioners and researchers in the medical profession, who wish to use standardized tests for DHH sign language users.

In **Chapter 4** we studied the nature (sections 4.1 & 4.3) and impact (section 4.2) of possible barriers in accessing healthcare.

We used the guideline described in Chapter 2 to translate four standardized questionnaires into Sign Language of the Netherlands (NGT). The first three are internationally standardized questionnaires that have been translated and validated successfully in over a dozen languages. They do not require a high level of language development and have been widely field-tested. The fourth is especially developed for use by DHH participants. The questionnaires are:

- *World Health Organization Quality of Life-BREF (WHOQoL-BREF)*: a short quality of life questionnaire that met our methodological demands and explicitly evaluates participants' physical health.
- *The General Health Questionnaire (GHQ)*: a screening instrument for identifying minor psychiatric disorders. It can be used in the general population or with clients in non-psychiatric clinical or primary care settings. We used the GHQ-12, the shortest version, especially designed for research studies.
- *The KIDSCREEN*: a generic quality of life instrument that has been designed and validated for children and adolescents between the ages of 8 and 18 years. KIDSCREEN can be used as a screening, monitoring and evaluation tool in health surveys. It

covers 10 health related quality of life dimensions, while many QoL questionnaires for children cover only psychological and schooling domains.

- *Deaf Acculturation Scale (DAS)*: This is a 58-item scale which measures deaf and hard of hearing individuals' degree of acculturation to both deaf and hearing cultures. It consists of two overall acculturation scales: a deaf acculturation scale (DASd) and a hearing acculturation scale (DASh). Both measure acculturation across five domains. The DAS is the only validated scale that provides information about the cultural status of DHH persons. Having a different cultural identity from the majority society may have a negative effect on interaction. The DAS can be used to evaluate such effects among DHH people.

We also further translated a non-standardized epidemiological questionnaire, a medical questionnaire and a General Practitioner (GP) communication list.

Section 4.1 describes the results of our pilot study where we explored the communication between 32 severely DHH patients and their general practitioners (GP). Both the patients and their GPs filled out a questionnaire regarding communication during the consultations. We were interested to discover whether we would be able to detect communication barriers. The questionnaires were based on similar studies in hearing ethnic minority groups and were offered in written Dutch only.

The information which was compiled using the questionnaires indicated that communication problems are experienced in more than one third (39%) of the contacts between a deaf patient and their GP. Comparable studies between GPs and patients from ethnic minority groups in the Netherlands, reported that communication problems were experienced during 33% of the contacts, compared to 13% of the contacts when patients have a shared cultural and linguistic background with their GP. Arriving at a diagnosis and recommending a suitable therapy are the main goals of a consultation with a GP. We found that GPs are more positive about their ability to communicate this information than their patients. Over 90% of the GPs think that they are often or always able to explain the diagnosis and treatment clearly to their patients, while only slightly more than half of the patients stated that their GPs were often or always able to explain the diagnosis and treatment clearly.

We found that sign language or speech-to-text interpreters are hardly ever used during GP consultations. However, another factor that may contribute to the communication problems is that generally, GPs are not aware of the existence of a Deaf culture (83%) and, as a consequence of this, are also unaware of possible cultural differences.

Section 4.2 describes the quality of life of deaf and hard of hearing adults in the Netherlands. The physical and mental health of 274 DHH participants was measured using the World Health Organization Quality of Life- Bref scale (WHOQoL-BREF). Participants filled out an epidemiological questionnaire and questions about the language mode they generally use. The results were compared with those of a population-based control group. We found that different groups of DHH people experienced significantly more physical difficulties than the control group. This difference was highly significant in the group of people who were DHH from a young age. This outcome agrees with other studies.

Scores for psychological health were higher (better) in the deaf groups than in the hard of hearing groups: In contrast to other studies, deaf participants in the Netherlands did not report more psychological problems than the control group. Possible reasons for the differences in this perceived quality of life in physical and psychological domains are discussed, including the possible impact of barriers in healthcare access.

Very few incidence/ prevalence studies on public health and healthcare provision include DHH people as a specific group. We concluded that the health issues of DHH patients deserve further study to enable avoidance of medical, ethical and legal problems. More awareness and knowledge concerning the specific health problems of DHH people is necessary to enable appropriate and adequate healthcare provisions. DHH people and healthcare workers should be aware of the existence of co-morbidities and barriers to the access of healthcare, be educated on how to recognize and deal with these and when to consult an expert, specialized service or request communication assistance (e.g. a speech-to-text interpreter or sign language interpreter). Recognizing DHH people as a patient group requiring special attention is the first step towards improving their health.

Section 4.3 focuses on the Deaf cultural barriers that DHH people meet when they need to access the healthcare system. The quality of life of deaf and hard of hearing adults in relation to their degree of hearing loss, language skills, their relationship to the Deaf community and cultural feature was studied. Fourteen informants were interviewed about their healthcare experiences, a structured literature review was performed and the results of the DAS questionnaire in relation to the Health Related Quality of Life questionnaire are presented and discussed.

We identified six cultural differences between DHH and non-DHH people that obviously influence healthcare provision. These six are:

1) *Information processing:* Deaf community members are more likely to get information from each other and have less access to formal information sources.
2) *Manners:* Manners may differ between Hearing culture and Deaf culture; for example, ways to attract a person's attention, the processes of greeting and ending conversations.
3) *Lack of Trust:* Severely DHH children lack access to (ambient) information in hearing surroundings such as a health 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. On the other hand, many DHH people also continue to accept this lack of information as a fact of life; In our structured interviews it was reported that DHH people are less assertive when visiting their physician, which is also reported in the literature. For instance, Deaf people may agree more readily to diagnostic tests and treatments without understanding what the tests comprise, why they are done or what the (side) effect of the treatment is, more readily than their hearing peers
4) *Small community/ need for confidentiality:* As the Deaf form a closely-knit group, Deaf people may be even more reluctant than hearing people to discuss sensitive topics such as psychological problems or HIV transmission. It may even prevent them from using specialized medical and social services. It is important for non-Deaf healthcare workers 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*: Healthcare workers need to make sure they that they do not underestimate their DHH patients and offer sufficient information at the appropriate intellectual level.
6) *Dissemination of Information:* DHH research results need to be presented in a way which is comprehensible for DHH people. Unfortunately this need is often not addressed.

In this section we also focused on the relation between the primary mode of communication and health related quality of life. There are many debates in the literature and in (clinical) practice about who may benefit from the use of sign language, and to what extent it needs to be used to be beneficial. We found a significantly positive relationship between physical and psychological health, and the use of sign language and/or supporting signs. It appeared that the beneficial effect of using as many modes of communication as possible, is stronger than the possible negative effects of learning a language only partially. We did not find that a minimal ability to use sign language or supporting signs was necessary for these positive effects, the effect was present among all DHH groups. The relationship was continuous: the more extensive use of sign (language) a person has, the higher the score on the QoL scales.

In **Chapter 5** we studied specialized healthcare facilities for DHH people.Specialized psychological and psychiatric healthcare for deaf and hard of hearing clients has become available during the last fifty years. Over the last twenty years specialized general health facilities and ICT facilities supporting communication between care givers and sign language users also gradually started to emerge.

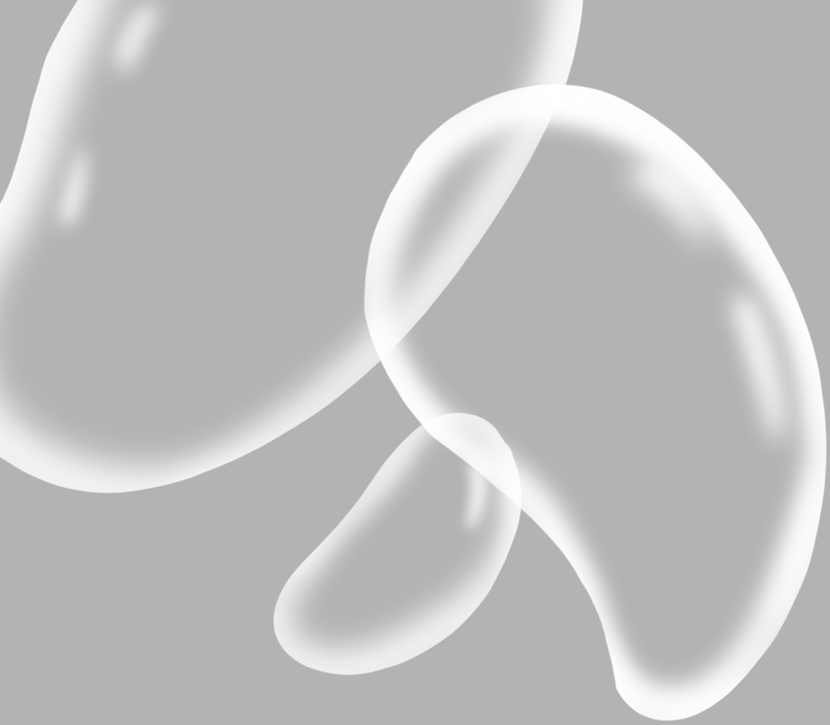
In **section 5.1**. we described the services that are used worldwide to facilitate this patient group. These services can be organized into 5 types of services:

1) ICT services and (remote) interpreting. Certified sign language interpreters are provided in 31 countries. It is unknown how many of these countries also provide speech-to-text interpreting. Eight of these countries are currently also providing remote interpreting services during medical consultations.
2) Health promotion activities. As part of our literature search we found 33 articles on healthcare knowledge and promotion projects. The great majority of these articles concerned HIV/AIDS prevention. From interviews, we know that the number of educational projects that are started is much higher than reported in the literature. Numerous small, local educational projects are probably initiated. Some countries are now developing websites or other multi-media carriers providing information on mental health issues for DHH people. In the USA, some local projects have been set up that focus on providing medical patient information in sign language, but to our knowledge no national projects have been undertaken to make general medical information easily accessible to the DHH population.
3) Specialized primary healthcare, GP services and health clinics. The UK and Norway report having specialized primary healthcare facilities such as general practitioners with some SL skills, and knowledge of the special health needs of DHH people. No research papers describing these facilities and their effectiveness were found.
4) Specialized secondary healthcare, outpatient clinics. To our knowledge Austria, Switzerland, France and Japan are the only countries that provide special outpatient clinics for DHH people. These facilities also usually provide support for the medical staff involved when DHH people are hospitalized in their hospitals (inpatient services). Experts and patient groups report a higher perceived quality of healthcare and quality of health education within these specialized clinics. There are no scientific studies to support or reject these findings.
5) Mental health facilities. At least 17 countries provide specialized inpatient and/ or outpatient clinics for DHH people. Though most of these described services are likely to be cost-effective, there are no reliable scientific data available to support this assumption.

In **section 5.2** we evaluated a specialized outpatient clinic for DHH people in the Netherlands. We set up a quantitative research protocol to evaluate the functioning and effect of this clinic. The initiative failed and was terminated after two years, leaving us with insufficient data to perform an original quantitative study. A new qualitative research protocol was written and implemented, using structured and non-structured questionnaires and structured interviews to analyze the start-up, functioning and closedown. Based on the lessons learned from this project we made recommendations for the set-up of such a facility in the future. The main lessons learned were that diverse DHH groups should be involved from the beginning, that the type of healthcare provision should match the needs of the DHH groups, that the facility should be initiated and run by people with relevant and sufficient expertise, and that sufficient time should be invested in the start-up and in gaining the trust of the groups of DHH patients.

In **conclusion** we found that DHH people face significant barriers in accessing healthcare. This is similar to the barriers faced by patients from other (ethnic) minority groups. The barriers in providing healthcare for severely DHH patients can be classed as follows: a) Communication barriers, b) Barriers due to limited health knowledge and c) Deaf cultural barriers which influence healthcare provision to DHH people.

The lower quality of healthcare might be reflected in the fact that DHH people have a lower perceived quality of life in physical and psychological domains. Linguistic and Deaf cultural barriers to access to treatment are not recognized by healthcare workers. Several countries provide specialized facilities to improve healthcare access for this patient group. Though most of these services are likely to be cost-effective, no scientific data are available to support this assumption.



7.2

Nederlandse samenvatting

Nederlandse samenvatting

De reden voor het opzetten van dit onderzoeksproject was heel persoonlijk. Als arts en taalkundige merkte ik dat het beeld dat veel artsen van de medische hulpverlening aan dove en slechthorende (DSH) patiënten hebben, sterk verschilt van het beeld dat dove en slechthorende patiënten zelf hebben van de medische hulpverlening en van artsen.

Collega-artsen vertelden mij dat zij helemaal geen problemen ervaren in de hulpverlening aan deze patiëntengroep: de meeste DSH patiënten kunnen immers goed liplezen, en als ze het niet verstaan wordt de informatie toch voor ze opgeschreven? Veel medische informatie staat tegenwoordig op internet, dus dat kunnen DSH patiënten thuis gewoon opzoeken en nalezen. Bovendien ervaren veel artsen DSH patiënten als een relatief makkelijke patiëntengroep, bij navraag zijn ze bijvoorbeeld juist vaker therapietrouw dan andere patiëntengroepen.
Wat de artsen betreft geen probleem dus!

Als taalkundige vertelden veel DSH mensen mij dat zij negatieve ervaringen hadden in hun contacten met artsen en andere medische hulpverleners. Uitspraken als 'dokters geven geen uitleg, ze vertellen alleen wat je moet doen' en 'medische hulpverleners behandelen ons als verstandelijk beperkt`, maken dat met name binnen de Dovengemeenschap veel mensen de medische wereld wantrouwen. Velen gaven aan van mening te zijn dat er niet valt te communiceren met artsen, hier wordt dus wel degelijk een probleem ervaren.

Nieuwsgierig geworden naar deze discrepantie in belevingen, begon ik onderzoek te doen naar de eventuele communicatieproblemen tussen DSH patiënten en hun medische hulpverleners. Toen bleek dat de omvang en het type problemen in de medische hulpverlening aan DSH patiënten vergelijkbaar is met de medische hulpverlening aan patiënten afkomstig uit etnische minderheidsgroepen, is deze eerste studie door de jaren heen uitgegroeid tot een aantal grotere onderzoeksprojecten.

Doel

Het doel van ons project was om te onderzoeken welke specifieke problemen er spelen in de medische hulpverlening aan dove en slechthorende patiënten, hoe groot de gevolgen van deze problemen zijn en hoe zij eventueel verholpen kunnen worden. De resultaten van dit project kunnen gebruikt worden om de gezondheidszorg aan DSH patiënten in Nederland op een gelijkwaardig niveau te brengen met de medische hulpverlening aan goed horende Nederlanders.

DSH

In Nederland wordt ongeveer 1 op de 1000 kinderen doof of ernstig slechthorend geboren, in de loop van het leven neemt dit aantal toe tot 1,6 per 1000 op de tienerleeftijd en 88 per 1000 op 65-jarige leeftijd. Deze groep mensen is enorm divers. Zij verschillen onderling onder andere door de mate van gehoorverlies, de leeftijd waarop het gehoorverlies ontstaat en het niveau van taalontwikkeling. Het verschilt van persoon tot persoon in welke mate ze vaardig zijn in het gesproken Nederlands en/of de Nederlandse Gebarentaal (NGT) en of ze kunnen profiteren van medische hulpmiddelen zoals hoorapparaten en cochleaire implantaten. Ook de mate waarin mensen gebruik kunnen maken van ondersteunende vaardigheden, zoals bijvoorbeeld liplezen en leesvaardigheden, verschilt. Die enorme diversiteit maakt het moeilijk en duurder om goed wetenschappelijk onderzoek te doen. Daarnaast is er een tekort aan onderzoekers die de vaardigheden en kennis hebben om deze complexe onderzoeken te kunnen uitvoeren. Dit maakt dat er wereldwijd relatief weinig onderzoek gedaan is naar de gezondheid van DSH patiënten. Het onderzoek dat er wel is, is niet altijd van goede kwaliteit.

Methodologie

Onderzoeksresultaten zijn alleen betrouwbaar als de methode van onderzoek past bij de onderzoeksgroep en bij de onderzoeksvragen. Het aanpassen en valideren van gestandaardiseerde onderzoeksmethoden voor gebruik binnen de verschillende DSH patiëntengroepen is complex en tijdrovend. Het gevolg is dat vaak niet-gespecialiseerde testmethodes worden gebruikt, maar deze leveren onbetrouwbare resultaten op. Er bestaat een internationale richtlijn die voorschrijft hoe gestandaardiseerde vragenlijsten vertaald, cultureel aangepast en gevalideerd moeten worden voordat ze gebruikt kunnen en mogen worden in een andere gesproken taal. Deze richtlijn is niet geschikt voor het vertalen naar gebarentalen. Daarom hebben we in overleg met onder andere onderzoeksgroepen in Duitsland en Amerika een internationale richtlijn ontwikkeld voor het vertalen naar gebarentalen.

Wij hebben vier gestandaardiseerde vragenlijsten, conform deze nieuwe richtlijn, vertaald naar Nederlandse Gebarentaal. Deze vier zijn: de WHO-QoLbref, de KIDSCREEN, de GHQ-12 en de DAS vragenlijst. Daarnaast hebben we ook van deze lijsten versies in Nederlands met Gebaren ontwikkeld. Deze vragenlijsten zijn gebruikt voor sommigen van de onderzoeken in dit proefschrift. Om een volledig beeld te krijgen is naast dit kwantitatieve vragenlijstenonderzoek ook gebruik gemaakt van literatuuronderzoek en kwalitatieve onderzoekmethoden zoals het verzamelen van ‘expert opinions’, het verrichten van gestructureerde interviews en gebruik van niet-gestandaardiseerde vragenlijsten.

Opzet van het proefschrift

In secties 2 t/m 4 hebben we onderzocht hoe de medische hulpverlening aan DSH patiënten verschilt van de medische hulpverlening aan patiënten zonder doofheid of slechthorendheid, wat er misgaat en wat de mogelijke gevolgen hiervan zijn. In sectie 5 kijken we naar mogelijke oplossingen om de medische hulpverlening aan DSH patiënten te verbeteren.

Sectie 2 beschrijft inleidend de medische, ethische, juridische en communicatieve dilemma's waar medisch hulpverleners rekening mee moeten houden als ze met DSH kinderen te maken hebben. Een belangrijke valkuil hierbij is dat mensen geneigd zijn vooral met de horende (volwassenen) te spreken, waardoor DSH kinderen niet de kans krijgen om, los van hun ouders, hun eigen verhaal te vertellen. Daarnaast missen DSH kinderen informatie die horende kinderen wel mee zouden krijgen. Dit werkt door tot in de volwassenheid.

Sectie 3 beschrijft hoe wij een internationale richtlijn hebben ontwikkeld voor het vertalen en intercultureel aanpassen van gestandaardiseerde geschreven vragenlijsten naar een gebarentaal.

Sectie 4: Beschrijft de aard (sectie 4.1 & 4.3) en omvang (sectie 4.2) van de mogelijke barrières in de toegang tot gezondheidszorg. In **sectie 4.1** staan de resultaten van ons pilotonderzoek naar de communicatie tussen 32 dove-/ernstig slechthorende patiënten en hun huisartsen. Uit de vragenlijsten bleek dat tussen 39% van de huisartsen en dove-/ernstig slechthorende patiënten communicatieproblemen werden ervaren. Vergelijkbare studies onder huisartsen en hun patiënten afkomstig uit etnische minderheidsgroepen in Nederland geven aan dat er in 33% van de huisarts-patiënt relaties communicatieproblemen worden ervaren, terwijl tussen huisartsen en patiënten met dezelfde taal- en culturele achtergrond, slechts 13% van de mensen communicatieproblemen ervaren. Uit dit pilotonderzoek bleek dat om financiële en logistieke redenen vrijwel nooit schrijftolken of tolken Nederlandse Gebarentaal worden ingezet bij de huisarts. Daarnaast waren de meeste huisartsen überhaupt niet op de hoogte van het bestaan van het fenomeen 'Dovencultuur' en van het feit dat sommigen van hun patiënten Nederlands Gebarentaal als moedertaal hebben.

Sectie 4.2 beschrijft de resultaten van een onderzoek naar de fysieke en mentale gezondheid van 274 DSH deelnemers, gemeten met de WHO-QoLbref kwaliteit van leven vragenlijst. Hun resultaten zijn vergeleken met een (horend) cohort uit de Nederlands populatie.

Uit onze resultaten blijkt dat de verschillende DSH subgroepen significant meer lichamelijke (gezondheids-) problemen ervaren dan de controlegroep. De slechthorende groepen, maar niet de dove groepen, scoorden ook significant slechter op het gebied van psychische problemen. Dit is bijzonder, omdat in onderzoek naar psychische problemen bij DSH mensen in andere landen onder zowel dove als slechthorende deelnemers significant meer psychische problemen werden gevonden dan onder horenden. Er zijn verschillende verklaringen te bedenken waarom slechthorenden in Nederland meer psychische problemen ervaren dan doven. Eén daarvan is dat er in Nederland tot voor kort een groot gespecialiseerd netwerk was van psychische hulpverlening voor dove patiënten. Deze was laagdrempelig toegankelijk voor alle doven, terwijl slechthorende mensen niet snel in gespecialiseerde psychische hulpverlening terecht zullen komen. Andere verklaringen voor de lagere psychologische kwaliteit van leven van slechthorende volwassenen in vergelijking met dove volwassenen kan zijn dat een licht of matig gehoorverlies vaak pas laat wordt/werd ontdekt. Hierdoor kunnen kinderen met een lichte of matige slechthorendheid lange tijd tegen problemen in de sociale interactie en school-/leerproblemen aanlopen zonder dat zijzelf of de omgeving weet waar dit vandaan komt. Dit kan leiden tot onzekerheid, een lager zelfbeeld en een lagere psychologische kwaliteit van leven. Daarnaast zien we dat slechthorenden vaak het gevoel hebben nergens echt bij te horen/nergens echt goed mee te kunnen komen. Zij horen niet in de dovengemeenschap maar passen ook niet goed in de ‘horende gemeenschap’. Dit zou ook de lagere psychologische kwaliteit van leven mede kunnen verklaren.

Sectie 4.3 beschrijft de culturele verschillen tussen doven en slechthorenden versus mensen zonder gehoorbeperking. We hebben de culturalisatie van 235 DSH volwassenen in Nederland onderzocht en gekeken naar de mogelijke effecten ervan op hun gezondheid.Een (sub-) cultuur kan gevormd worden door een groep mensen die een gezamenlijke achtergrond, sociale ervaringen en/ of gezamenlijke normen en waarden delen. Veel DSH mensen hebben beperkt toegang tot de gesproken taal en zijn op momenten uitgesloten van de ‘horende samenleving’ of ‘horende cultuur’. Jongeren die doof of ernstig slechthorend opgroeien zijn zich vaak bewust van de geschiedenis van doven en slechthorenden en de meesten van hen ervaren gemeenschappelijke sociale en persoonlijke kenmerken/problemen die voortkomen uit, of samenhangen met, het gehoorverlies. Dit maakt dat mensen die doof zijn opgegroeid en die gebruik maken van gebarentaal, - sinds de jaren 80 van de vorige eeuw - gezien worden als leden van een speciale subcultuur: de Dovencultuur. In de afgelopen jaren is gebleken dat deze culturele (sub)groep breder is dan dove gebarentaalgebruikers alleen. Alle mensen die doof of matig tot ernstig slechthorend opgroeien, vertonen en/of ervaren in meerdere of mindere mate doof-culturele kenmerken. Culturele verschillen kunnen dus zowel bij dove als bij slechthorende patiënten de medische hulpverlening beïnvloeden.

Wij hebben onderzoek gedaan onder 235 DSH volwassenen (60 doof, 175 slechthorend). Zij hebben onder andere de Deaf Acculturation Scale ingevuld; een vragenlijst die meet in hoeverre iemand zich identificeert met, en kan meedoen aan, de horenden cultuur enerzijds en de Doven cultuur anderzijds. In onze groep haalden 118 mensen een bi-culturele score (zowel hoog scoren op schaal voor horende culturele kenmerken als op schaal voor doof culturele kenmerken), 54 mensen bleken horend geculturaliseerd, 14 mensen doof geculturaliseerd en 54 mensen marginaal geculturaliseerd (geen horenden cultuur en ook geen doven cultuur). Opvallend is dat de dove deelnemers significant hogere (=betere) culturalisatie scores hadden dan de slechthorende deelnemers. Er werd een positieve correlatie gevonden tussen de verschillende kwaliteit van leven subschalen en de mate van zowel dove als horende culturalisatie. Uit dit onderzoek blijkt dat het type taal (gesproken of gebarentaal) en het type cultuur (meer horend of doof geculturaliseerd) geen effect hebben op de mate van lichamelijke- en/of psychische problemen die iemand ervaart. De mate van taalbeheersing (hoe goed en hoe veel taal je kent) en de mate van culturalisatie (ben je onderdeel van een (sub)cultuur waarin je volwaardig mee kan doen) hebben daar wel een significant effect op en ook op de kwaliteit van leven. Zowel de mate van kwaliteit van leven als de mate van culturalisatie zijn multifactorieel bepaald; ze worden door heel veel verschillende factoren beïnvloed. Op basis van de cijfers in dit onderzoek wordt 2.8%- 11.7% van de kwaliteit van leven beïnvloed door de mate van culturalisatie.

Sectie 5: In de afgelopen 60 jaar is een wereldwijd netwerk van in DSH gespecialiseerde psychische hulpverlening ontstaan. Sinds ongeveer 20 jaar ontstaat er ook her en der hulpverlening gericht op de lichamelijke gezondheid van DSH mensen.

De soorten initiatieven die zijn ontstaan hebben wij ingedeeld in 5 groepen: 1) ICT-projecten en tolken op afstand, 2) preventieve gezondheidsprogramma's en specifieke voorlichting gericht op DSH mensen, 3) gespecialiseerde eerstelijnszorg bestaande uit gezondheidscentra en huisartsen, 4) gespecialiseerde tweedelijnszorg bestaande uit gespecialiseerde ziekenhuizen en poliklinieken, 5) gespecialiseerde psychische gezondheidszorg. In **sectie 5.1** geven we een overzicht van deze verschillende soorten initiatieven, hun locaties wereldwijd en voor zover mogelijk hun effectiviteit.

In **sectie 5.2** beschrijven we het opzetten van een in DSH patiënten gespecialiseerde polikliniek genaamd PoliDOSH in Boxtel, Nederland. Het PoliDOSH-initiatief mislukte; er kwamen te weinig patiënten om kostenefficiënt te zijn. We beschrijven het proces van het opstarten van PoliDOSH, bespreken de knelpunten en geven adviezen hoe een dergelijk initiatief in de toekomst wel een succes zou kunnen worden. Belangrijke leerpunten zijn dat het project geïnitieerd moet worden door de DSH patiëntengroepen zelf en dat zij gedurende het proces betrokken moeten blijven bij de invulling van het project; de hulpverlening die geboden gaat worden moet aansluiten bij de behoeften van DSH patiëntengroepen. Daarnaast moet het project geleid worden door mensen met voldoende ervaring en relevante expertise op het gebied van de betreffende vorm van (medische) hulpverlening en op het gebied van hulpverlening aan DSH patiënten. Tot slot heeft een dergelijk project tijd nodig: het kost tijd om de juiste expertise te verzamelen, tijd om bewustzijn en bekendheid te krijgen onder reguliere medische hulpverleners en tijd om het vertrouwen van de DSH patiënten te krijgen.

Er is kwalitatief goed wetenschappelijk onderzoek nodig naar de aard van de gezondheidsproblemen van dove en slechthorende patiënten, hun effecten op lange termijn en de effecten van gespecialiseerde gezondheidszorg. Er worden in de internationale literatuur twee redenen gegeven waarom de hoeveelheid onderzoek tot nog toe beperkt is:

1. Wetenschappelijke onderzoek op gebied van DSH wordt vrijwel altijd gefinancierd door audiologische industrieën. Zij zijn geïnteresseerd in onderzoek naar het verbeteren van het gehoor (medisch model) maar aanzienlijk minder in onderzoek naar het verbeteren van de hulpverlening, uitgaande van een bestaand gehoorverlies (sociaal model). Het is hierdoor heel moeilijk om onderzoek vanuit een sociaal model gefinancierd te krijgen
2. Het aantal onderzoekers met voldoende medische, taalkundige en DSH sociaal-culturele kennis om dit onderzoek goed uit te kunnen voeren is beperkt.

De problemen waar DSH mensen tegenaan lopen ten aanzien van gezondheidszorg zijn wereldwijd hetzelfde. Onderzoek naar de aard van de problemen zou dus heel internationaal uitgevoerd kunnen worden. Wat de beste/meest efficiënte manier is om de gezondheidszorg aan DSH patiënten te verbeteren is onder andere afhankelijk van de demografie en organisatie van de gezondheidszorg. Dit verschilt dus per land.

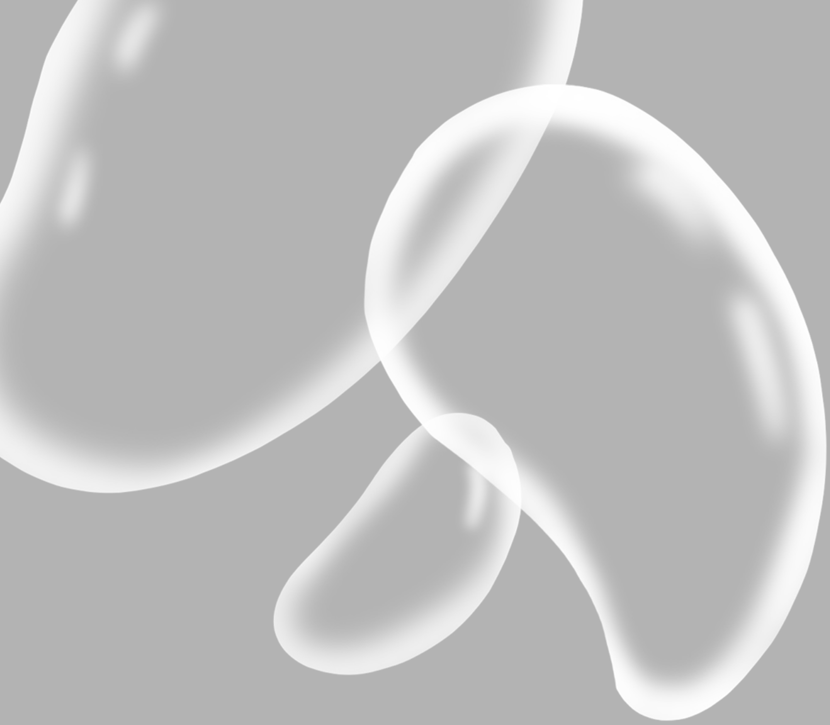
Conclusies

Dove en slechthorende mensen vormen een speciale patiëntengroep. De problemen die zij tegenkomen zijn qua inhoud en omvang vergelijkbaar met die van patiënten afkomstig uit etnische minderheidsgroepen. Dit heeft er mede toe geleid dat DSH mensen in Nederland aangeven een significant lagere lichamelijke en vaak ook psychische kwaliteit van leven te hebben dan de rest van de bevolking. In verschillende landen zijn initiatieven ontwikkeld om de gezondheidszorg aan DSH mensen te verbeteren; het is aannemelijk dat de meeste van deze initiatieven kosten-efficiënt zijn, maar hier is nooit goed onderzoek naar gedaan. Ik hoop dat dit proefschrift bijdraagt om de gezondheidszorg aan DSH mensen in Nederland op een vergelijkbaar niveau te brengen als die aan niet-DSH mensen.

Aanbevelingen

- Deze complexe patiëntengroep verdient het beste van beide werelden: goede medische hulpverleners gespecialiseerd in het specifieke medische probleem van de patiënten, die tevens gespecialiseerd zijn in medische hulpverlening aan DSH patiënten. Als dat niet mogelijk is: bundeling van krachten met in DSH gespecialiseerde medische hulpverleners en communicatiespecialisten.
- Vergroting van het bewustzijn voor het bestaan van DSH specifieke gezondheidsbehoeften is nodig. Allereerst onder DSH patiënten zelf. Zij moeten beter geïnformeerd worden over de verschillen in medische hulpverlening aan hen in vergelijking met horende patiënten, wat hun rechten zijn en hoe ze hierover in overleg kunnen treden met hun hulpverleners. Ten tweede onder gezondheidszorgmedewerkers, gezondheidszorgmanagers, beleidsmakers en verzekeraars.
- Gezondheidszorgmedewerkers tijdens hun opleiding informeren dat zij de vaardigheden die zij daar aanleren om beter om te kunnen gaan met de problemen van patiënten uit etnische minderheidsgroepen ook kunnen en moeten gebruiken in contact met DSH patiënten.
- Er moet goede en toegankelijke algemene gezondheidsinformatie en specifieke patiëntinformatie voor DSH mensen komen.
- Voorzieningen of projecten ter verbetering van de gezondheidszorg(toegang) voor DSH mensen moeten ontwikkeld worden in nauwe samenwerking met zowel zorgmedewerkers als de diverse DSH groepen. Belangrijk is dat de projecten voorzien in de lokale behoeften van DSH mensen.
- Betere inzet en ontwikkeling van ICT-voorzieningen ter ondersteuning van de gezondheidszorg aan DSH patiënten in een reguliere setting.
- Ontwikkeling van meer op DSH gerichte diagnostische instrumenten.

In Nederland zou het creëren van een onafhankelijk, nationaal expertisecentrum een passende vorm kunnen zijn om bovenstaande aanbevelingen te helpen realiseren.



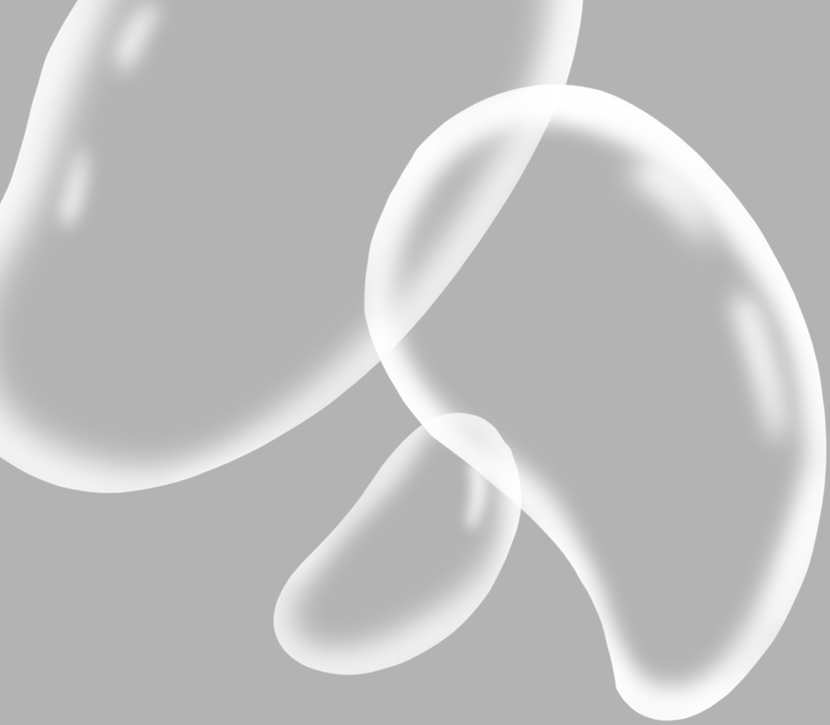
7.3

Samenvatting in Nederlandse gebarentaal

Samenvatting in Nederlandse gebarentaal

De samenvatting in Nederlandse gebarentaal is te zien op;

www.zorgbeter.info



APPENDIX

Abbreviations
Publications
Biography
Dankwoord

Abbreviations

AMC:	Amsterdam Medical Centre
ASL:	American Sign language
CI:	Cochlear implant
dB:	Decibel
DAS:	Deaf Acculturation Scale
DASd:	Deaf acculturation scale
DASh:	Hearing acculturation scale
DHH:	Deaf or Hard of Hearing
GHQ:	General Health Questionnaire
GP:	General Practitioner
HBO:	Higher occupational schooling
HoH:	Hard of hearing
HI:	Hearing impaired: including both deaf and hard of hearing patients
HRQoL:	Health-related quality of life
LBO:	Lower occupational schooling
MBO:	Average occupational schooling
MD:	Medical doctor
MHoH:	Mild hard of hearing
MRI:	Magnetic resonance imaging
NGT:	Nederlandse Gebarentaal (Sign Language of the Netherlands)
SHoH:	Severe hard of hearing
SL:	Sign Language
WHOQoL-BREF:	World Health Organization Quality of Life-BREF scale
WO:	University degree

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Smeijers AS, Ens-Dokkum M, van den Bogaerde B, Oudesluys-Murphy AM. Deaf cultural features & healthcare - An overview of current knowledge and new insights. Submitted

Biography

Anika Smeijers was born on March 24th, 1980 in Amsterdam, the Netherlands. She graduated from secondary school (Atheneum) at het Solyvius College in Hoofddorp in 1998. In the same year she started her study of medicine at the University of Amsterdam. In 2002 she started her second study of linguistics with a specialization in sign linguistics. For her study she performed a research project on the communication between general practitioners and deaf and hard of hearing patients. During her study she was a member of the student council and had several other (board)functions.

In 2006, Anika started to work as a resident (ANIOS) in pediatrics in the Mesos Medisch Centrum in Utrecht. In September 2007 she started working with hearing impaired patients as a resident in psychiatry at GGZ De Gelderse Roos in Ede, department ‘De Riethorst’. ‘De Riethorst’ is specialized in providing both inpatient and outpatient mental health care for deaf and hard of hearing adults and elderly. From October 2007 until July 2008 she combined this function with a residency in child and adolescent psychiatry at Curium- Leiden University Medical Centre (LUMC) in Leiden, where she initially worked at the department ‘De Vlier’, the only national center providing both in- and outpatient mental health care for deaf and hard of hearing children and adolescents. After July 2008 she continued working full time at Curium-LUMC, working for the neuroteam (outpatient clinic for children with neurological or language disorders), the adolescent open observational ward and the intensive care ward. From July 2009 until January 2011 Anika worked as a resident (ANIOS) in pediatrics in the Spaarne Ziekenhuis in Hoofddorp.

From February 2011 until June 2011 she worked as an MD in Haydom Lutheran Hospital in Tanzania. Here she focused on providing daily medical care at the neonatal unit, training the nurses and running an implementation project for phototherapy.

In March 2012 Anika started her training in pediatrics at the LUMC and the Reinier de Graaf Gasthuis (Tutor: Dr. W.J.W. Kollen, Dr. B. Bakker).

After her registration as a pediatrician in 2016, she worked as a locum pediatrician at the Slingeland hospital in Doetinchem and at the Spaarne Gasthuis in Hoofddorp.

Since 2016, she is working as a resident, pediatrician and fellow at the department of social pediatrics, Emma Children’s Hospital, Amsterdam UMC, location AMC (Tutor: A.H. Teeuw). Since 2016, she is one of the pediatricians in the LECK (Landelijk Expertise Centrum Kindermishandeling, Dutch National Expertise Center Child Abuse) and one of the pediatricians in the Centre for Sexual Violence (Centrum Seksueel Geweld)

Amsterdam- Amstelland. During this period she participated in the KOALA outpatient social pediatrics department at the Spaarne Gasthuis) and the MDCK (Multidisciplinair Centrum Kindermishandeling Kennemerland, Multidisciplinary Center Child Abuse Kennemerland).

During medical school, her internships and her work as a resident, Anika designed, collected funding and performed several research projects on healthcare for deaf and hard of hearing people. This has resulted in this thesis. Anika is a member of the European Society for Mental Health and Deafness (ESMHD) and has given many national and international lectures on healthcare provision for deaf and hard of hearing people.

Dankwoord

Ik ben enorm dankbaar dat zoveel mensen de afgelopen tien jaar, vaak belangeloos, hebben bijgedragen aan dit onderzoek. Zonder ieder van hen was het nooit gelukt.

Om te beginnen wil ik alle deelnemers en respondenten bedanken die deel hebben genomen aan onze studies. Er zit vaak veel tijd tussen het moment dat deelnemers gevraagd worden mee te doen en het verschijnen van de resultaten van een onderzoek. Jullie hebben belangeloos jullie tijd geïnvesteerd zonder zeker te weten of en wanneer er eindelijk resultaten kwamen. Dank voor het in mij gestelde vertrouwen! Daarnaast verdienen de Belangenorganisaties een ereplekje: Bestuur en leden van FODOK, FOSS, NVVS, Dovenschap, Stichting Plotsdoven en Laatdoven en OPCI: Jullie input was de basis voor dit onderzoek. Dank voor jullie hulp bij het formuleren van de onderzoeksvragen en voor jullie hulp bij het werven van participanten. Ik hoop dat de uitkomsten jullie werk kunnen ondersteunen.

Prof. dr. Anne Marie Oudesluys-Murphy: Jij hebt van begin af aan vol enthousiasme naar mijn onderzoekidee gekeken. Door de steun van jouw en Martina werd het werkelijkheid. Hoe lang het ook duurde en hoeveel tegenslagen er ook kwamen, je bleef positief!
Prof. dr. Beppie van den Bogaerde: Wat is het fijn samenwerken met jou! Gezellig, efficiënt en elkaar af en toe feilloos aanvullen. Ik hoop dat er nog veel meer gezamenlijke projecten gaan volgen.
Dr. Martina Ens- Dokkum: Toen ik nog veel twijfels had of ik wel zelf onderzoek wilde doen, maar wel precies wist te vertellen wat en hoe er onderzocht moest worden, was jij het die mij met Anne Marie in contact kwam, nooit verwacht dat dat zoveel jaren later zou resulteren in deze promotie! Dank je wel voor je altijd kritische en nuchtere commentaar, de artikelen zijn daar een stuk scherper van geworden.

Marijke Scheffener: Dank voor je (letterlijk) onbetaalbare bijdrage aan dit onderzoeksproject. Jij hebt mij mijn eerste gebaren geleerd en gaf mij het vertrouwen om, ondanks niet altijd perfecte grammatica, te blijven communiceren. Na o.a. ADH en ZorgBeter ben je niet meer alleen docent en collega, maar ook vriendin geworden.
Mariska Bijsterveld: Wat was het gezellig... dank voor al je hulp!
Roland Pfau: Door de studie taalwetenschap raakte ik enthousiast voor het doen van wetenschappelijk onderzoek. Ook al leek het soms hopeloos, uiteindelijk heb ik van jou zó leren schrijven zodat ik de wetenschap nu ook zelf een beetje kan beoefenen.
Lianne Dijkstra en Willem Terpstra: Dank voor jullie hulp bij de vertalingen.

Maarten, John en Henk: Beste mannen, slapeloze nachten, vele filmversies en honderden extra corrigerende filmbewerkingen maakte ´jullie vertaling´ tot een van de uitdagendste onderdelen van het onderzoek. Bedankt voor jullie inzet en vooral, heel veel dank dat jullie het hebben volgehouden.
Stagiaires Maaike, Djoeke, Aina, Brenwan en Marianne: Dank voor jullie vele uren hulp en enthousiaste deelname aan het onderzoek. Zonder jullie had ik waarschijnlijk nog steeds geen Facebook account gehad.
ESMHD (European Society of Mental Health and Deafness): Johannes Fellinger, Lauri Rush, Steven Powel, Renata Sarmento, Stefania Fada, Beate Ohre, Anne Harmsen, Maria Wisnet, Robert Pollard, Inez Sleeboom, Tio van Gent: You’re my international inspiration!
Ron Wolterbeek (statistiek), Just Eekhof en Joke Haafkens (huisartsgeneeskunde LUMC en AMC): Dank voor jullie advies!
’t Hok: Fase 1: Linda, Annelies, Tjitske, Liselotte. Fase 2: Cor-Jan, Ilona, Danny. Gezellige Sinterklaasavondjes, oneindig veel lunches en spui-uurtjes, bedankt voor de gezelligheid en voor de alle promtie tips en trics.
Nederlandse Spoorwegen (NS): 90% van dit boekje is geschreven in publieke ruimtes, waarvan de helft in de trein; ontelbaar veel km kantoor op rails in 3 jaar tijd! Altijd rustig werken en op tijd aankomen. De trein rules! (Met eervolle vermelding voor Connexxion, luchthavens, een aantal Nederlandse, Ierse, Griekse, Engelse en Spaanse hotels, een groot aantal koffietentjes en af en toe een weekje Center Parcs voor de andere helft).
Dank aan ‘NSGK voor het gehandicapte kind’ en ‘Stichting Handgebaar’ voor jullie financiële bijdrage aan dit onderzoek.
Dank aan ‘Phonak Nederland’ voor de ondersteuning bij het werven van participanten.

Tien werkplekken in binnen en buitenland in 10 jaar. Dank aan alle lieve collega’s voor jullie flexibiliteit! In het bijzonder:
Collega´s GGZ De Riethorst: Jullie zijn een geweldig team, zorg dat dat altijd zo blijft.
Charly Erkens: Beste Charly, bedankt voor de inspirerende discussies en de kansen die ik heb gekregen om mij binnen De Riethorst te ontwikkelen, zij liggen aan de basis van dit proefschrift. Dank dat je mij in de ESMHD hebt binnen gebracht. Otto Fritschy: Dank dat je me naar De Riethorst, een van mijn belangrijkste leerscholen in de Dovenwereld, hebt gehaald. Marc Opstal en Marileen Lauwers: Ondanks de al beperkte middelen in psychiatrie en ondanks dat we elkaar nog maar kort kenden, hebben jullie het aangedurfd om uren te investeren in mijn onderzoek. Zonder jullie lef was dit project niet geworden tot wat het nu is.
Collega´s Curium-LUMC: Ruth, Ymeen, Inge, Claudia, Annet, Cinta, Kees, Josje, Nelleke, Marja en Roel; In roerige tijden leer je elkaar goed kennen. Wat was het fijn om met jullie samen te werken en van jullie te leren. Johannet van Geloof: Jij hebt de eerste steen verplaatst die maakte dat mijn onderzoeksidee werkelijkheid werd. Robert Vermeire:

Dank voor het op gang helpen van mijn onderzoek en de kansen die ik binnen Curium heb gekregen.
Peter de Winter en alle collega´s van het Spaarne ziekenhuis 2009- 2010: Dank voor het opstapje (terug) naar de kindergeneeskunde. Fijn dat jullie het met mij uitgehouden hebben, ook als ik weer eens maar vijf uur had geslapen.
Collega's van het LUMC; dank voor leerzame levenslessen. Wouter Kollen; als opleider en manager ben je een groot voorbeeld. Secretariaat: Mirjam Vollebregt, Inge Durmus- van Well, Wendy Matthijsen en Yvonne van der Kwast- Engberts: Een troostend woord als ik er even doorheen zat of gewoon even samen lachen, jullie secretariële ondersteuning de afgelopen 10 jaar was goud waard. Mede dankzij jullie ben ik nu kinderarts. Heel veel dank ook weer voor jullie hulp in deze laatste fase.
Boudewijn Bakker, Claire Woltering en alle collega's van de kindergeneeskunde in het Reinier de Graaf ziekenhuis: dank voor de gezellige en leerzame tijd!
Spaarne Gasthuis 2017- heden: KOALA-team Andrieke, Elles, Erica, Gracita, Marian, Tjitske, Marieke, Joyce en Kim. Wat een warm en deskundig team, ik heb veel van jullie geleerd en hoop jullie in de toekomst nog heel vaak te zien.
Sociale pediatrie Amsterdam UMC: Al bijna 4 jaar mag ik onderdeel zijn van deze unieke vakgroep. Dromen, hard werken, passie en frustraties; of het nu innovatief onderzoek is of idealistische zorg verlenen, beiden gaan gepaard met een achtbaan van emoties. Machtelt, Michelle, Thekla, Sonja, Rick, Marie-Louise, Kirsten: Dank jullie wel dat ik bij jullie af en toe mijn frustraties mocht spuien en dank voor jullie hulp bij de laatste loodjes van dit proefschrift. Hulpverlenen vanuit liefde, betrokkenheid en bevlogenheid is zwaar en ongelooflijk mooi. Dank jullie wel Rian en Annemarie dat ik hierin van jullie mag leren. Het is een voorrecht om jullie als opleiders en collega's te hebben.

Joke: Vriendin en gebarentaalmaatje. Dank voor de vruchtbare discussies en het spiegelen van promotieleed. Ik hoop dat er nog veel gezamenlijke congressen en fietstochtjes volgen.
Ilona: Dank voor je onvoorwaardelijke vriendschap, gezellige vakanties en eindeloze avonden samen met Cees en de kids.
Sigrid: Sauna- en studiemaatje, hopelijk trekken we nog heel veel levensfases samen op.
Kirsten en Evelien: Al hebben de 'ladiesnights' hun oorspronkelijke functie verloren, we zijn er nog lang niet klaar mee! Op naar de volgende cocktailnight.
Musicalmaatjes Rosanne & Wendy: Dank voor de gezellige avondjes.
Werkgroep Dovenhistorie Amsterdam: Annemieke, Jolanda, Dick, Ans, Menno en overige (oud)leden van de vrijdaggroep: Dank voor jullie begrip als ik af en toe wat minder tijd had. Ik geniet van de gezellige samenwerking, al vele jaren lang!
Badmintonmaatjes (na ampel overweging heb ik besloten hier toch maar niet de naam van onze app groep neer te zetten): dank voor de sportieve afleiding.

En dank aan alle overige vrienden die de afgelopen tien jaar langere of kortere tijd samen op hebben gelopen: Lous van der Voorst- Schinning. Saskia Rombach, Joline Vons, Ana en Tannie Hasraten de MIC-cers.

Guido & Ronald: Wat bijzonder om dit met jullie te mogen meemaken.
Tante Coby: Mijn trouwste supporter en tijdbewaker. Wat fijn dat u er vandaag bij bent.
Martijn & Meriel: Lief broer(tje), ik hoop dat je ook de rest van mijn leven mijn maatje blijft. Lieve Meriel, wat ben ik blij met jou als schoonzus!
Papa en mama: Dank voor de veilige basis die maakt dat ik af en toe eigenzinnig durf te zijn. In mijn werk zie ik hoe zeldzaam waardevol een liefdevolle en onbezorgde jeugd is. Ik voel mij zeer bevoorrecht met jullie als ouders. Dank voor de tientallen werkstukken en artikelen die jullie door de jaren heen hebben nagelezen. Door jullie steun en rotsvaste vertrouwen ben ik hier gekomen!

Opgedragen aan Gerard Smeijers, opa, voorbeeld en beschermengel.