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## 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 conversation 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.<sup>1</sup> 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.<sup>2</sup> 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.<sup>3</sup> 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.<sup>4,5</sup> 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.<sup>6</sup> 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.<sup>7-9</sup> 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.<sup>4,10</sup> 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.<sup>11-13</sup> 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 discuss 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.