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

Smeijers, A.S.

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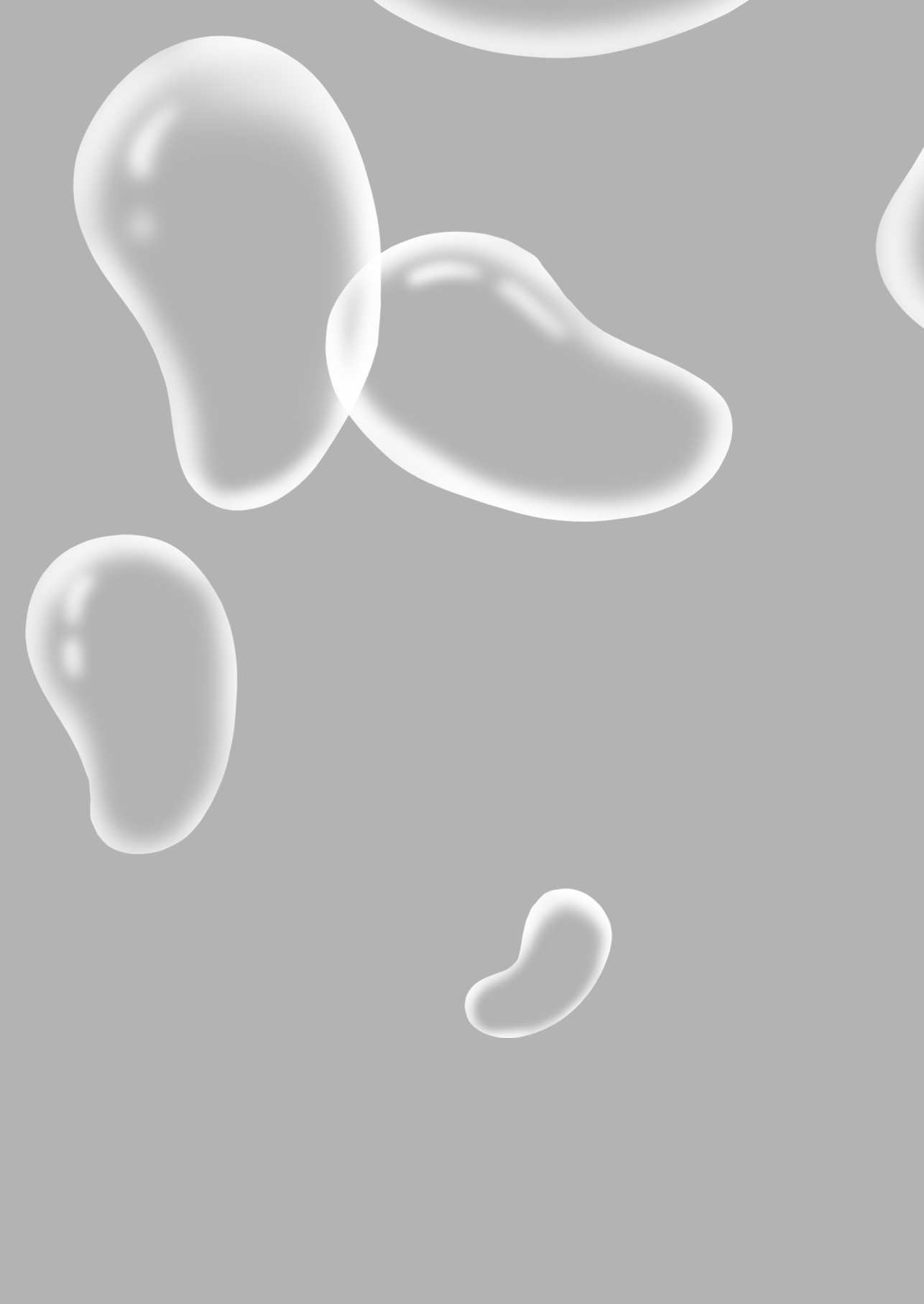


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# 4.3

## 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, ethno-history 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 ethno-history 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; Kritzing, 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, Fellingner, & Fellingner, 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 data. 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
<b>Year of birth</b>				
• 1985-1993	10.1%	4.8%	2.3%	Population based control group was matched for age, gender and level of education for all three DHH groups separately.
• 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%	
<b>Gender</b>				
• Female	71.7%	71.2%	52.3%	
• Male	25.0%	28.1%	45.5%	
• Unknown	3.3%	0.7%	2.2%	
<b>Level of education</b>				
• 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%	
<b>Employment</b>				
	66.7%	53.2%	60.6%	
<b>Have cochlear implant</b>				
	34.9%	12,2%	2.0%	
<b>Language use</b>				
• 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 losses, 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).

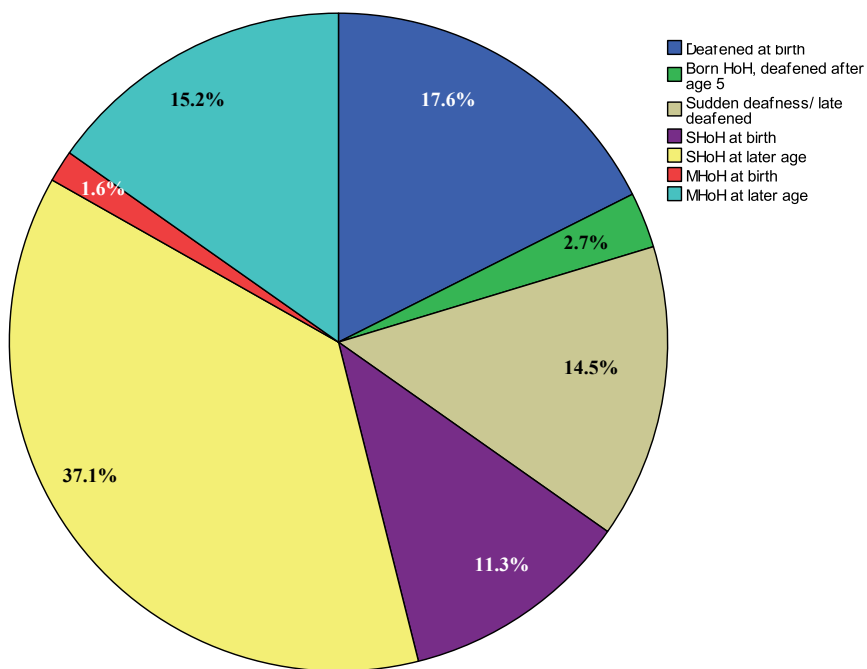


Figure 1: DHH subgroups.

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

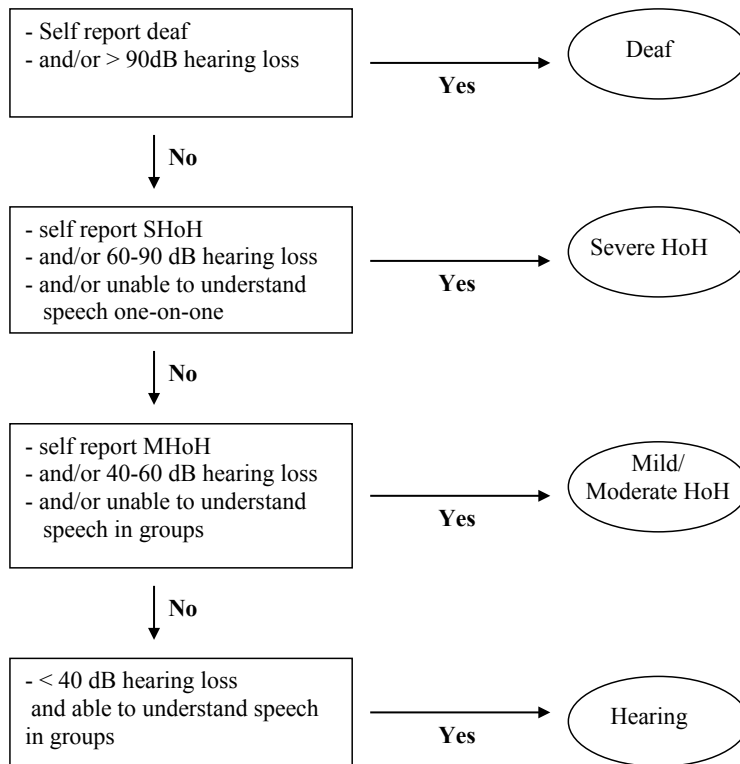


Figure 2: Classification of amount of hearing loss.  
dB loss is measurement report of best ear.

### **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 ( $R^2$ ) 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)	0.0413x10 <sup>-12</sup> **	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)	0.0985x10 <sup>-3</sup> **	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		P
		Deaf before age 5 vs GPop	SHOH before age 5	
Physical	63.85 (17.28)	0.001*	56.40 (18.07)	0.012x10 <sup>-3</sup> **
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		P
SHOH vs GPop	MHOH	MHOH vs GPop
0.0276x10 <sup>-24**</sup>	50.26 (18.00)	2.28x10 <sup>-12**</sup>
0.624x10 <sup>-6**</sup>	59.00 (11.33)	0.285x10 <sup>-6**</sup>
0.2266x10 <sup>-3**</sup>	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<sup>19</sup> (\*p<0.05, \*\*P<0.001)

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

	P		P		P
Deaf after age 5	Deaf after age 5 vs GPop	SHOH after age 5	SHOH after age 5 vs GPop	L/MHOH after age 5	MHOH after age 5 vs GPop
59.62 (17.58)	0,034x10 <sup>-3**</sup>	56,03 (16,84)	9.064x10 <sup>-15**</sup>	50,00 (17,05)	1.6708x10 <sup>-9**</sup>
67.71 (12.38)	0.549	63,40 (11,26)	0.512x10 <sup>-3**</sup>	59,76 (11,10)	0.077x10 <sup>-3**</sup>
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<sup>19</sup> (\*p<0.05, \*\*P<0.001)



**Table 5:** Mean scores of participants on DASd and DASH scale. Higher scores correspond with higher grade of acculturation.

	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 <sup>-11**</sup>	P= 5.3x10 <sup>-9**</sup>
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<sup>19</sup> (\*p<0.05, \*\*p<0.001)

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

**Table 6: Correlation between Deaf acculturation scale and QoL.**

	Deaf acculturation (DASd)		Hearing acculturation (DASH)	
	P-value	R <sup>2</sup>	P-value	R <sup>2</sup>
<b>Physical QoL</b>	7.68x10 <sup>-5**</sup>	0.061	4.63x10 <sup>-6**</sup>	0.081
<b>Psychological QoL</b>	6.92x10 <sup>-7**</sup>	0.094	2.62x10 <sup>-8**</sup>	0.117
<b>Social QoL</b>	5.55x10 <sup>-4**</sup>	0.047	0.003*	0.035
<b>Environmental QoL</b>	0.036*	0.018	0.059	0.014

The table shows the p values and the determination coefficients (R<sup>2</sup>) 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 acculturation a person has, the higher the score on the QoL scales.

It could be hypothesized that people who experience better health, have higher acculturation 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 acculturation 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.

Acculturation 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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