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

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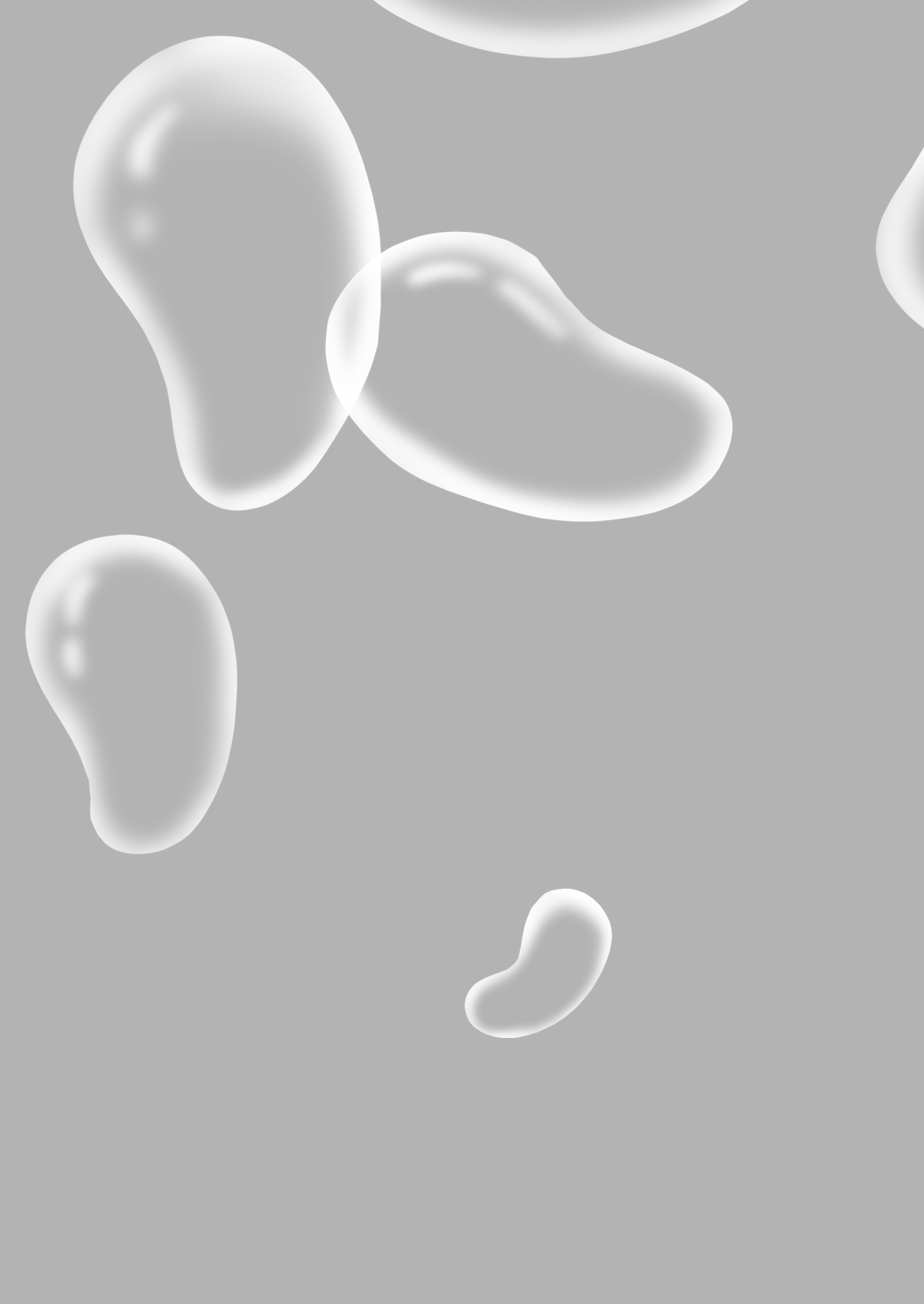
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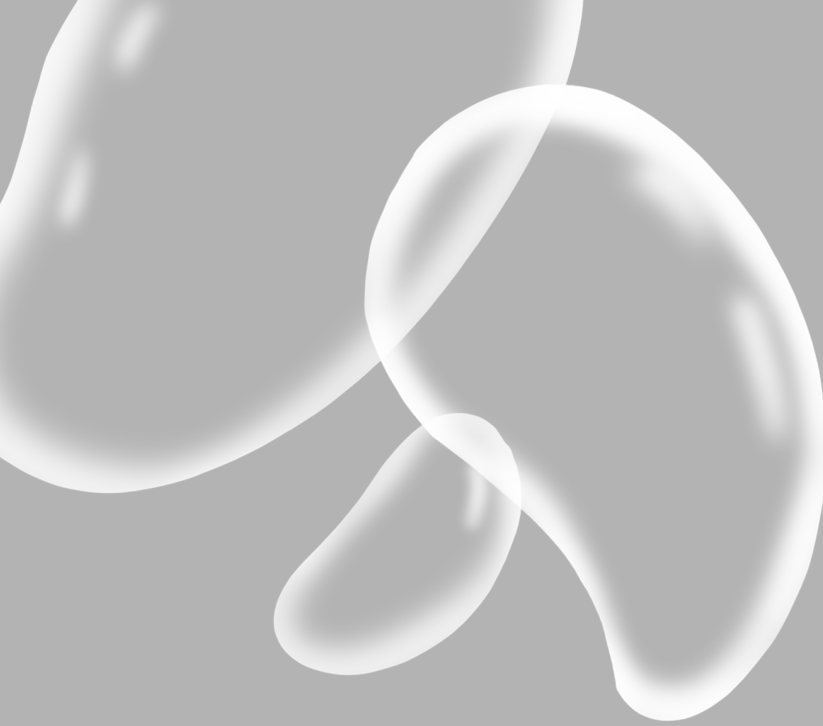
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4

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

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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)	32%
	or university degree (WO)	
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.

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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.
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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.

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