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

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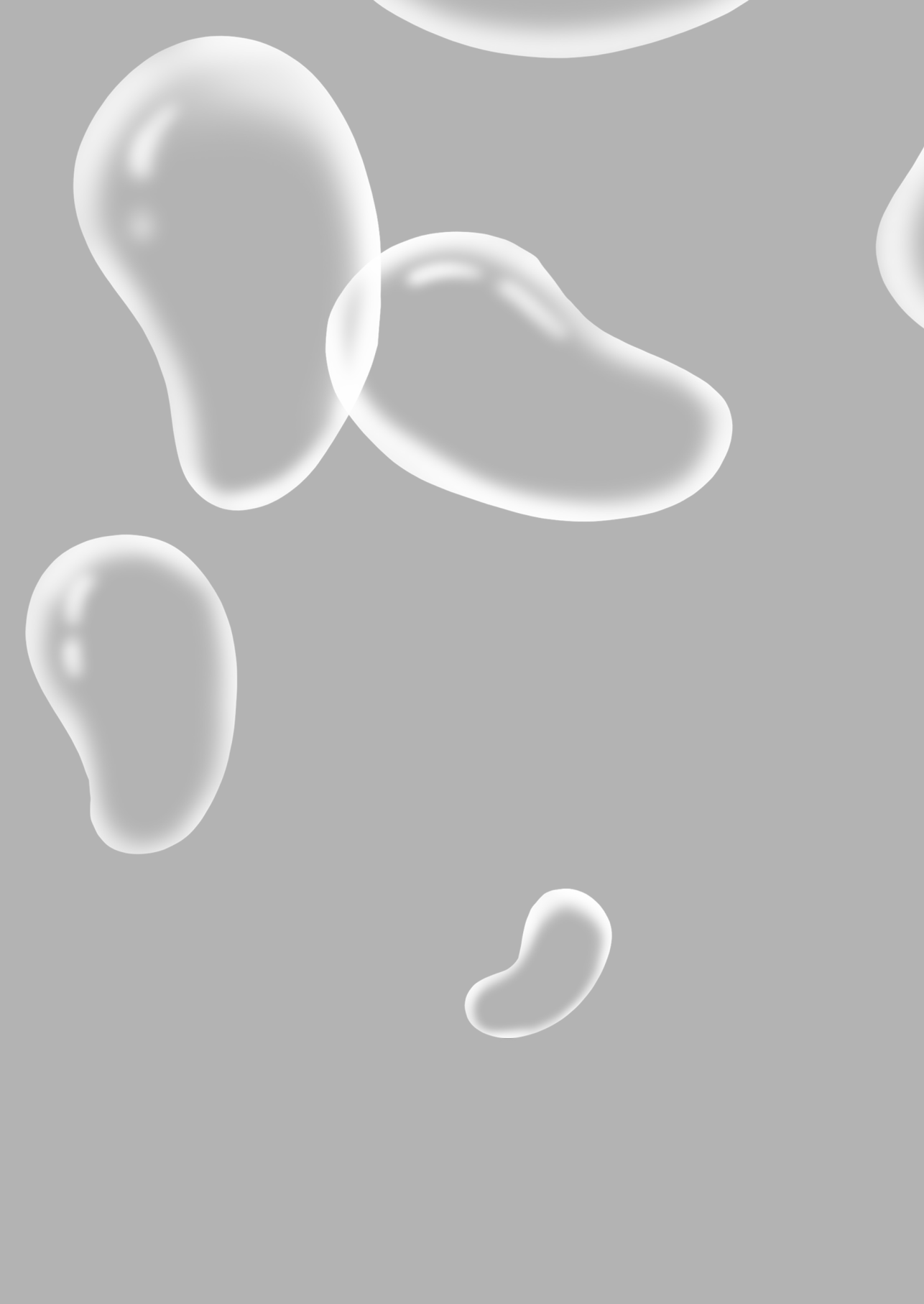
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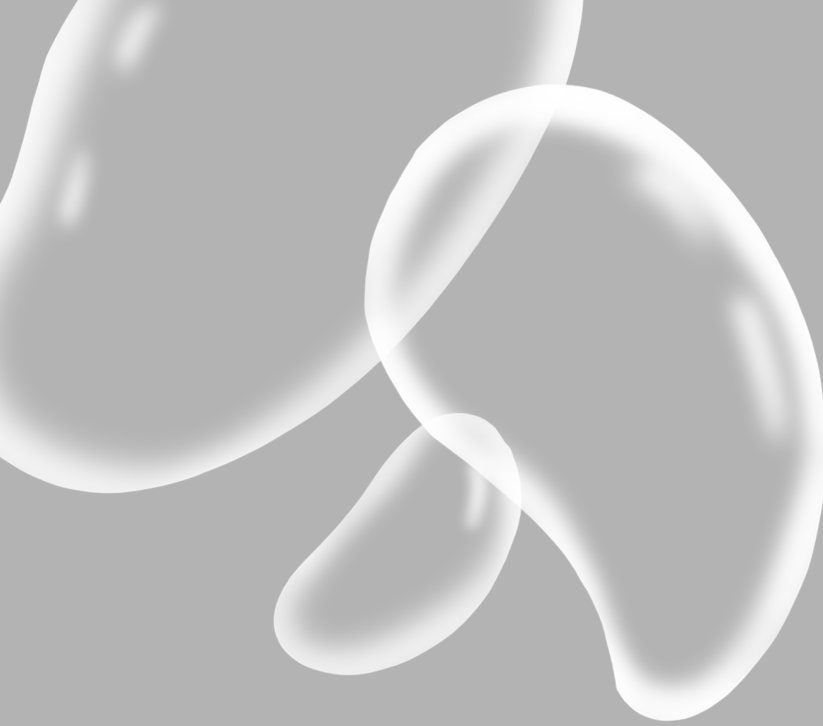
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5

Healthcare facilities for deaf and
hard of hearing people





5.1

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

Published article:

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Abstract

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

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

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

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

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

Introduction

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

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

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

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

DHH adults often have limited knowledge concerning health and disease^{5, 6}. Restricted exposure to many topics in schools for DHH children contributes to this⁷. Most DHH people do not have access to 'ambient information', they do not overhear conversations or hear radio and television announcements^{5,8,9}, and low literacy is also a factor in people who are severely DHH from a young age¹. Information from newspapers, magazines, internet and television captioning is less accessible than it is for hearing people. Thus, DHH adults have limited access to information that many hearing adults would consider common knowledge⁵. Healthcare workers often assume that DHH patients can understand them by lip-reading. However, not all DHH learn to lip-read and even a highly skilled lip-reader can only 'read' 30-40 percent of spoken language by watching the lips of a speaker, the other 60 percent has to be guessed¹⁰. Since many unfamiliar words are used during a medical consultation, this mode of communication has been proven to be inadequate^{2,11}.

Since the special needs of the DHH are related to both cultural and linguistic barriers, they are often compared with other minority groups in the literature^{5,12,13}. Physicians are not aware of these similarities which often cause communication difficulties. DHH people frequently report that physicians do not understand them¹⁴⁻¹⁶ and physicians are even less likely to try to repeat explanations than when communicating with immigrants¹⁶. As a corollary to this, DHH people are the only non-native speakers of the local spoken language who may be judged to be mentally retarded if they are incapable of composing a grammatically correct spoken sentence¹⁶.

Effective communication with DHH patients is important in healthcare, as inadequate communication may lead to wrong diagnoses and misguided therapy^{17,18}. Physicians are often not sufficiently prepared for caring for DHH patients as academic curricula do not include the necessary competences to meet the needs of this population¹⁹. Healthcare facilities and technical support facilities are being developed to improve medical access for these patients. Most of these facilities focus on meeting communication needs, some also meet cultural needs.

The main objective of this study is to obtain insight into the various general health facilities available to provide healthcare that complies with the special needs of DHH. Mental health facilities for the DHH have been described extensively⁴, therefore, in this article, the information on mental health is restricted to the influence of mental healthcare on general healthcare and vice versa.

Methodology

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

Systematic review

Criteria for considering studies for this review.

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

Search methods for identification of studies.

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

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

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

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

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

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

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

Data collection and analysis

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

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

Results

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

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

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

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

Table 1: Articles included in systematic review

Studies	Authors	Country of study	Year	Type of study
<i>Special outpatient clinics for DHH patients</i>	Fellinger et al ²⁰	Austria	2005	Descriptive
<i>Specialised educational programmes for DHH patients</i>	Kaskowitz et al ²¹	USA	2006	Program evaluation
	Folkins et al ⁸	USA	2005	Program evaluation
	Choe et al ²²	USA	2009	Program evaluation
	Jones et al ²³	USA	2005	Descriptive
	Jensen et al ²⁴	USA	2013	Program evaluation
	Hickey et al ²⁵	USA	2013	Program evaluation
	Harry et al ²⁶	USA	2012	Program evaluation
	Yao et al ²⁷	USA	2012	Program evaluation
<i>Evaluation of effectiveness of SL interpreters in healthcare settings</i>	Sacks et al ²⁸	USA	2013	Program evaluation
<i>Evaluation of effectiveness of SL interpreters in healthcare settings</i>	MacKinney et al ²⁹	USA	1995	Case-cohort evaluation study
<i>Evaluation of SL interpreters and SL training for professionals within maternity setting.</i>	Equy et al ³⁰	France	2012	Descriptive
<i>National (pilot) program to improve access, choice and control over maternity care</i>	Sporek PE ³¹	UK	2014	Descriptive
<i>Training medical students</i>	Thew et al ³²	USA	2012	Descriptive
Studies	Authors	Country of study	Year	Type of study
<i>Healthcare Access Among Deaf People</i>	Kuenburg et al ³³	Austria	2016	Review

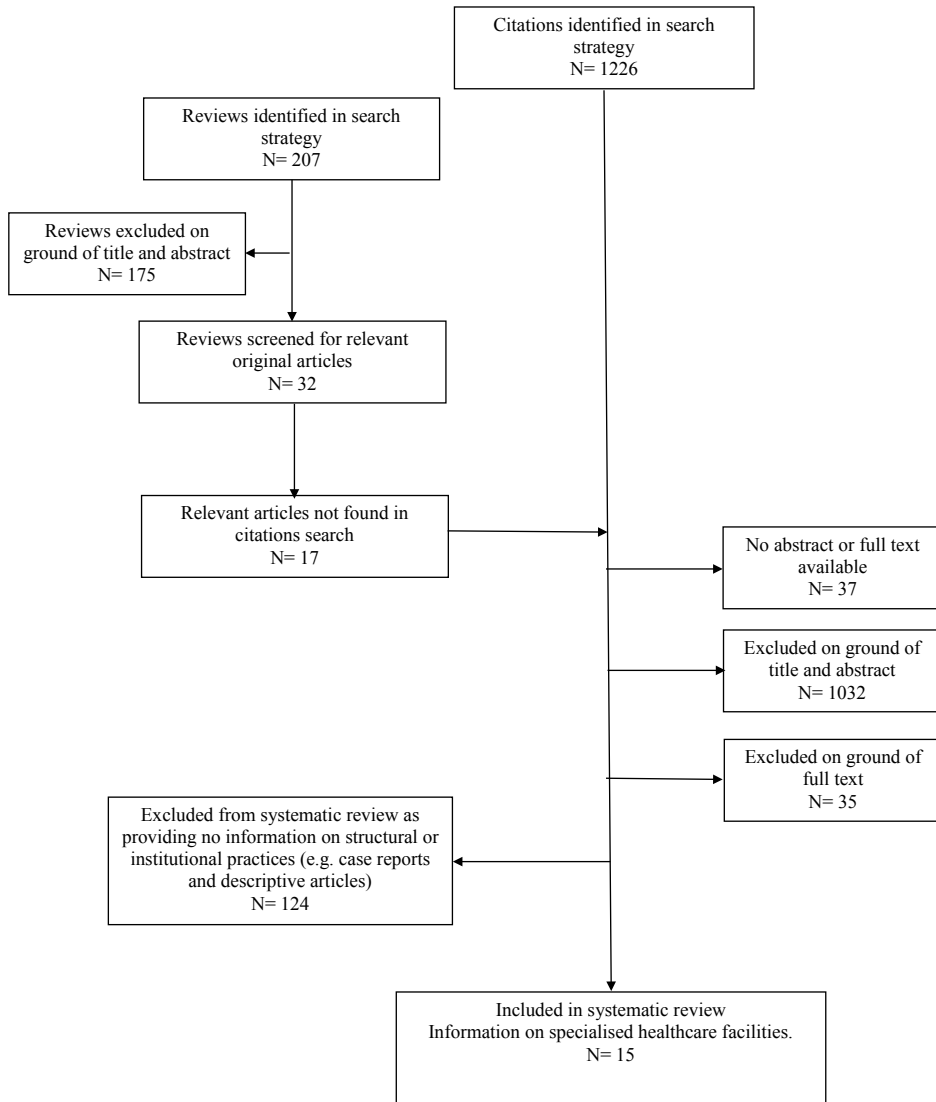


Figure 1: Flow diagram of literature search

Table 2: Overview of healthcare facilities for DHH.

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

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

* Facility available only regionally.

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

We found 30 countries where it is possible for healthcare staff to contact a qualified sign language interpreter³⁶. The standards for qualification differ worldwide. In this table we included countries where SL interpreters are certified, receive payment for their services and can be contacted through SL interpretation services, as listed in Table 2. Countries from which no recent information was available or where SL interpreters are available in only one city or region are not included in this list. Little information is available on how SL and speech-to-text interpreters, are trained to act in medical situations. Many countries reported that the number of interpreters is insufficient to provide a service in all required situations. To overcome the shortage of SL interpreters and/or to provide interpreting services in emergency situations, remote (online) interpreting facilities are available in Denmark, France, the United Kingdom (UK), Norway, Spain, Sweden, the USA, Australia, Finland and Japan. No studies on costs and/ or effectiveness are available⁴⁹. One study investigated the effectiveness of the use of American Sign Language (ASL) interpreters in a primary care programme. DHH persons enrolled in this programme had easier access to ASL interpreters than the control group. The participants who used ASL in medical situations were more satisfied with physician communication and had some improved preventive care outcomes²⁹.

In the UK and Spain a medically orientated online translation database is available which healthcare workers can log into for support when faced with a DHH sign language user. In the UK this system was developed by a non-profit organisation called SignHealth which coordinates all specialised healthcare facilities for DHH people in the UK. SignHealth has connected a translation programme to a (remote) online interpreting system, which enables the caregivers to switch to online interpreting when communication using the translation programme alone is unsatisfactory. No international publications exist on the usefulness of these translation facilities. The British developers reported that it is a useful low budget system in situations where no sign interpreter is available. After the start of the programme, the use of live SL interpreters also increased. This was because users of the system reported that they preferred having a live interpreter present⁵⁰.

It is not known which countries provide speech-to-text interpreting for DHH people in medical settings. The extra time a healthcare employee needs to write or type information for a patient and the risk of loss of information might be overcome by the help of a speech-to-text interpreter. Several studies described the development of a system that shows speech captions on portable devices and micro displays, but its current accuracy is not yet satisfactory⁵¹. To our knowledge no experiments with telehealth (videoconferencing technology) have yet been reported in general medical settings even though several

organisations are using this for mental healthcare provision. Studies on telehealth mental healthcare provision indicate that telehealth can be regarded as an efficient and cost-effective option for delivering healthcare to the DHH population^{52,53}.

Health promotion activities

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

Health related knowledge of DHH

One study⁵⁴ reported that 48% of the 166 participants had inadequate health literacy in comparison with a hearing control group. As the participants in this study had a higher educational attainment than is to be expected, the authors stated that the general prevalence of inadequate health literacy among people who are DHH from a young age is likely to be higher than that reported in this sample⁵⁴. Other studies reported that DHH individuals have less cardiovascular health knowledge resulting in higher cardiovascular risk factors than the general population⁶.

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

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

Interventions to improve health related knowledge in DHH

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

Because of the presumed increased risk of cardiovascular disease among DHH people an educational intervention train-the-trainer model was developed in Arizona, USA. This model was successfully rolled-out locally. Cardiovascular health knowledge increased, but whether this has resulted in a decrease of cardiovascular risk factors among the participants is yet to be evaluated²³. Several studies mentioned small non-HIV related health education curricula and programmes for DHH people. Some of these involved education on general health and disease, others on sexual health, prevention of alcohol and/ or tobacco abuse or improvement of oral hygiene⁵⁹⁻⁶².

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

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

One article described a training programme in Rochester, USA³² for medical students to become more aware of the issues that arise when caring for patients with DHH. We know from the interviews that training is also available for some medical students in Northern Ireland, Ireland⁶⁴ and the Netherlands. These programmes do not have a structural character yet and their effect must be evaluated.

Specialised primary healthcare and health clinics

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

Specialised secondary healthcare, outpatient clinics

Austria, Switzerland, Japan and France provide special outpatient clinics for DHH patients (Table 2). The first three countries mainly focused on providing healthcare in their special outpatient clinic itself. France mainly focused on supporting the communication of non-specialised healthcare staff in other (in/ out-)patient clinics. All these facilities also provide support to the medical staff involved when DHH patients are hospitalised in their hospitals (inpatient facilities). In Austria, France and Switzerland these facilities are supported through public financing. Experts and patient groups reported a higher perceived quality of healthcare and quality of health education within these specialised clinics²⁰. There are no scientific studies to support these findings.

Discussion

It is difficult to get a clear view of special healthcare facilities globally available for people who are severely DHH. Availability of facilities changes and updated information is not easily retrieved. The information gathered from the systematic literature review, internet searches and interviews with workers in the field shows that while many countries attempt to improve facilities and communication with people who are DHH, the coverage is still poor and patchy. Even when facilities exist these have not been evaluated. Though the provision of specialised healthcare facilities for DHH individuals is quite haphazard, there seems to be a pattern in the order of facilities emerging in countries. Externalising behaviour, being problematic for society, seems to be dealt with first, resulting in specialised mental healthcare facilities^{66,67}. Relatively cheap and easy to implement facilities such as ICT facilities and the use of available SL interpreters in medical settings follow. Only when enough DHH people live within a certain region (usually larger cities or urban areas), when there is a high level of awareness of the special needs of DHH and when sufficient finance is available, is it possible for specialised general health facilities to emerge and succeed. Due to communication barriers, DHH people are easily overlooked and lag behind in political discussions⁶⁸. Therefore an important factor for successful healthcare provision to DHH people is the presence of enough DHH-aware pioneers and advocates who are able to mobilize and motivate healthcare providers, managers and politicians continuously.

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

It is known that the use of interpreters in medical settings is cost effective⁶⁹. No costs-benefits analyses are available on remote interpreting facilities. Costs are lower than when a live interpreter is used, however a remote interpreter is not identical to the presence of a live interpreter⁴⁹. Currently it seems that remote interpreting is mainly used when no interpreter would otherwise be used, e.g. emergency situations or situations that are considered to be too short or not important enough to bring in an interpreter. The use of remote interpreting is expected to grow in the coming years, so more research into this subject is needed.

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

All retrieved studies and all interviewed patient groups and experts described a lower level of health related knowledge among DHH persons. Several studies supported the hypothesis of patient groups that the information needs of DHH are not met during medical consultations¹³. Instead of providing more information to compensate for their pre-existing lower knowledge level, DHH people are often given even less information and explanations than hearing patients. Many projects have been undertaken to improve this knowledge level. Although two of these interventions were effective, the authors reported that more research is needed to determine what is the best and most cost-effective way to increase health related knowledge in this population⁷⁰. To our knowledge, structurally available specialised health education is provided only by special schools for DHH children and youth. Due to the high percentages of sexual abuse of DHH children, many schools have special programmes on sexual education. Up to now no reports of a change in abuse rates after introduction of these programmes are available.

Many facilities that aim to improve the health knowledge of DHH people are not structurally available on national scales but only temporarily for the duration of a project or only for a small group of DHH people. Current developments in technologies such as the wide availability of internet, offer opportunities to improve health knowledge of DHH people. Some preliminary studies exploring these opportunities are beginning to appear, e.g. from Kushalnager et al., who were the first to evaluate the accessibility and usability of some health websites for American SL users⁷¹.

The lack of structurally available programmes to improve health knowledge gives rise to ethical debates. Some authors discuss whether it is ethical to perform preventive medical tests when the patient's knowledge about these tests is poor, due to lack of information⁵⁸. This discussion is probably also applicable to diagnostic testing and therapies.

Strength and limitations

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

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

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

Implications for practice

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

Implications for future research

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

Conclusion:

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

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

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