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## Interventions aimed at improving healthcare and health education equity for adult d/Deaf patients: a systematic review

Morisod Kevin

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**UNIVERSITE DE LAUSANNE - FACULTE DE BIOLOGIE ET DE MEDECINE**

Département Vulnérabilités et médecine sociale

Secteur recherche et développement

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**Interventions aimed at improving healthcare and  
health education equity for adult d/Deaf patients:  
a systematic review**

THESE

préparée sous la direction du Professeur Patrick Bodenmann  
avec la co-direction du Professeur Joachim Marti

et présentée à la Faculté de biologie et de médecine de  
l'Université de Lausanne pour l'obtention du grade de

DOCTEUR EN MEDECINE

par

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Lausanne  
2023

## Résumé de Thèse MD (Kevin Morisod)

### **« Interventions visant à améliorer l'équité d'accès aux soins et à l'information pour les personnes sourdes adultes : une revue systématique. »**

#### **Contexte**

Selon l'OMS, plus de 460 millions de personnes dans le monde souffrent d'une perte auditive invalidante et sont considérées comme sourdes. Ces personnes souffrent d'un accès inéquitable aux soins et à l'information. Cela se traduit par une moins bonne littératie en santé et une moins bonne santé mentale et physique par rapport aux populations entendantes. Concrètement, elles sont plus à risque de développer des maladies chroniques au cours de leur vie, y compris l'hypertension et le diabète. Elles souffrent également de façon disproportionnée de problèmes de santé mentale tels que des troubles anxieux et de la dépression. Enfin, les personnes sourdes ont tendance à percevoir leur santé comme étant moins bonne que la population générale. L'objectif de cette étude est d'analyser systématiquement les interventions visant à améliorer l'équité en santé des personnes sourdes, en particulier concernant l'accès aux soins et à l'information.

#### **Méthode**

Nous avons recherché dans Medline Ovid SP, Embase, CINAHL EBSCO, PsycINFO Ovid SP, Central-Cochrane Library Wiley et Web of Science les études pertinentes sur l'accès aux soins et les interventions liées à la santé pour les personnes sourdes. La sélection, l'extraction, l'analyse et l'évaluation de la qualité des études de cette revue se sont faites en suivant les guidelines PRISMA-equity. Nous nous sommes concentrés sur les interventions visant à améliorer l'accès aux soins et à l'information pour les personnes sourdes.


#### **Résultats**

Nous avons initialement identifié 1507 articles, dont 46 ont été inclus dans l'analyse finale. Sept catégories d'interventions visant à lutter contre les iniquités d'accès aux soins ou à l'information sont apparues : le recours aux interprètes en langue des signes dans les soins (1), la traduction, validation et identification d'outils et d'échelles cliniques (2), les programmes de formation des professionnels de la santé à la prise en charge des populations sourdes (3), le développement d'établissements de soins adaptés (4), l'utilisation de la télémédecine (5), les programmes d'éducation à la santé (6) et les vidéos adaptées linguistiquement et culturellement (7). Malgré certaines limites méthodologiques ou le manque de données, ces interventions semblent pertinentes pour améliorer l'équité des soins et l'éducation à la santé des personnes sourdes.

#### **Conclusion**

Les résultats soulignent l'importance fondamentale de l'accès aux interprètes communautaires en langue des signes pour garantir l'équité des soins pour les personnes sourdes. La télémédecine peut améliorer cet accès pour pallier le manque d'interprètes en langue des signes dans certaines zones rurales ou socio-économiquement défavorisées. Toutefois, en l'absence d'une solution miracle, la voie à suivre pour améliorer l'équité en santé des personnes sourdes semble être la mise en œuvre et l'évaluation d'interventions adaptées au contexte. De plus, l'implication précoce des personnes sourdes dans le processus de recherche et de mise en œuvre de ces interventions semble être cruciale.

# Interventions aimed at improving healthcare and health education equity for adult d/Deaf patients: a systematic review

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**Background:** d/Deaf people suffer from inequitable access to healthcare and health information. This results in worse health literacy and poorer mental and physical health compared to hearing populations. Various interventions aimed at improving health equity for d/Deaf people have been documented but not systematically analyzed. The purpose of this systematic review is to obtain a global overview of what we know about interventions aimed at improving health equity for d/Deaf people. **Methods:** Medline Ovid SP, Embase, CINAHL EBSCO, PsycINFO Ovid SP, Central—Cochrane Library Wiley and Web of Science were searched for relevant studies on access to healthcare and health-related interventions for d/Deaf people following the PRISMA-equity guidelines. We focused on interventions aimed at achieving equitable care and equitable access to health information for d/Deaf people. **Results:** Forty-six studies were identified and analyzed. Seven categories of interventions facing healthcare or health education inequities emerged: use of Sign Language (1), translation, validation and identification of clinical tools and scales (2), healthcare provider training program (3), development of adapted healthcare facilities (4), online interventions (5), education programs (6) and videos (7). Despite some methodological limitations or lack of data, these interventions seem relevant to improve equity of care and health education for d/Deaf people. **Conclusion:** Interventions that promote healthcare equity, health education amongst d/Deaf patients and healthcare provider awareness of communication barriers and cultural sensitivity show promise in achieving more equitable care for d/Deaf patients. Meaningful engagement of d/Deaf individuals in the conceptualization, implementation and evaluation of health-related interventions is imperative.

## Introduction

According to the WHO, more than 460 million people worldwide have disabling hearing loss and are considered as d/Deaf.<sup>1</sup> The term ‘d/Deaf’ refers to individuals with severe to profound hearing loss (‘deaf’) which impairs communication, as well as to members of Deaf communities around the world (‘Deaf’), which are distinct cultural and linguistic minorities that use Sign Language to communicate and share common experiences and values. The term ‘d/Deaf’ does not include hard of hearing people (who refers to a hearing loss where there may be enough residual hearing that an auditory device, such as a hearing aid or FM system, provides adequate assistance to process speech). For Deaf communities, deafness is considered an alternative way of being, as opposed to a disability that requires correction.<sup>2</sup> Statistics concerning the number of individuals who identify as members of the Deaf community, however, are not well captured on a global scale but evidence from Canada suggests that they represent about 1 in 1000 individuals.<sup>3</sup>

International literature has highlighted that many health inequities are experienced by d/Deaf populations including barriers in accessing and receiving high-quality healthcare and in achieving optimal health outcomes.<sup>4–6</sup> Specifically, d/Deaf people have significant difficulties communicating with health professionals.<sup>7</sup> This is thought

to stem from a lack of access to Sign Language interpreters, as well as a lack of awareness and focused training in culturally appropriate communication with d/Deaf individuals amongst healthcare professionals.<sup>8,9</sup> This access to information extends beyond the healthcare setting, adversely impacting the health literacy of d/Deaf individuals who face limited access to hearing-based mass media, ambient conversations and public health messaging designed for the hearing world.<sup>10</sup> In fact, public health programs are often poorly adapted to this population which can have unintended negative consequences.<sup>11</sup> For example, during the AIDS epidemic in the 1980s, d/Deaf individuals long believed that AIDS was transmitted by solar radiation, following a poster campaign depicting the HIV virus over top of a large yellow mass resembling a Sun.<sup>12</sup>

With regards to health outcomes, evidence suggests that d/Deaf individuals experience worse health outcomes than the general hearing population.<sup>13</sup> For example, d/Deaf people are at greater risk of developing chronic diseases including hypertension and diabetes in their lifetime.<sup>14</sup> They also disproportionately suffer from mental illness<sup>15</sup> including anxiety and depression<sup>16,17</sup> and are at higher risk of suicide compared to hearing individuals.<sup>18</sup> Finally, d/Deaf people tend to perceive their health to be worse than the general hearing population.<sup>5,15</sup>

Over the past three decades, a rich body of literature has highlighted the barriers experienced by d/Deaf people in accessing

healthcare and in benefiting from public health or preventative health messaging, documenting the resultant inequities in health outcomes they experience.<sup>5</sup> However, there is a paucity of literature on solutions or ways forward in addressing these inequities.<sup>5,19</sup> In recent years, research teams around the world have begun to describe and evaluate interventions aimed at addressing and reducing health and healthcare inequities for d/Deaf people, in particular to improve their health literacy<sup>20</sup> through a better access to health informations or to develop specialized healthcare facilities for d/Deaf people.<sup>19</sup> However, to date this growing body of literature has not been systematically reviewed. The purpose of this article is to review what interventions have been described that aim to achieve equitable access to healthcare and health information for d/Deaf people, and of those what types of interventions show promise in improving health and healthcare equity for d/Deaf people.

## Methods

The protocol of this systematic review was published in PROSPERO at the outset of the study ([Supplementary file S1](#)). The reporting of this systematic review was based on the PRISMA-equity guidelines<sup>21</sup> ([Supplementary file S2](#)).

### Inclusion/exclusion criteria

We included studies reporting on interventions aimed at improving equity in healthcare and health education for d/Deaf people. We included all study designed (experimental, observational, quantitative or qualitative, longitudinal or cross-sectional), as long as a study described an intervention, assessed its role or compared its impact in a trial. If a study mixed epidemiological data with data regarding the impact of an intervention, we limited data extraction to data concerning the intervention. We chose to focus on d/Deaf people due to the specific needs and characteristics of this population. Studies focusing only on hard of hearing (HOH) people were excluded. If a study included both d/Deaf and HOH people, we limited data extraction to data concerning d/Deaf people only. We chose to focus on high-income countries, in order to limit the bias of the healthcare equity assessment due to the lack of resources that could affect the healthcare systems of low- and middle-income countries. We included studies on adults (age 18 and over). If a study included both children and adults, we limited data extraction to data pertaining only to adults. Searches were limited to articles in English, French and German (due to the language skills of the authors) published before December 2019.

We excluded studies that did not focus on equity, as well as opinion papers, reviews, editorials, conference abstracts and study protocols.

### Search strategy

The search strategy was conducted with the assistance of a medical librarian using six databases: Medline Ovid SP, Embase, CINAHL EBSCO, PsycINFO Ovid SP, Central—Cochrane Library Wiley and Web of Science. We used keywords in the field of deafness and health equity and healthcare accessibility. We combined the Medical Subject Headings (MeSH) terms ‘Health Services Accessibility’, ‘Health Equity’ or ‘Health Care Disparities’ with a combination of terms defining deafness and deaf people. With the help of a specialized librarian, we then translated and adapted the search equations to the different databases. The final search was conducted in December 2019. The full search strategy can be found in [Supplementary file S3](#). Following the initial search, to identify any further relevant studies that were not initially captured, we screened reference lists of all included studies and performed Google and Google Scholar searches using key search terms.

### Study selection

Two reviewers (KM and MM) screened articles independently and in duplicate. This was done in two stages. First by screening all titles

and abstracts and second, by reviewing the full text of all relevant articles to determine their eligibility in the final analysis. A third reviewer (PB) provided arbitration in the event of a disagreement at both stages of screening. Reasons for the exclusion of articles at the full-text screening stage were documented.

### Data extraction

Two authors (KM and MM) extracted data independently and in duplicate from included studies using Covidence<sup>®</sup>, a systematic review management software, and any discrepancies were resolved by consulting the third reviewer (PB). Data on key characteristics of the studies were extracted in a predefined data extraction form, into an Excel<sup>®</sup> spreadsheet. This included the design of the study, population, methodology, type of intervention, outcomes, main findings and key conclusions.

### Quality and bias assessment

The methodologic quality of each study was evaluated using the 2018 version of the Mixed Method Appraisal Tool (MMAT).<sup>22</sup> The MMAT was specifically designed to appraise studies with diverse study designs, including qualitative, quantitative and mixed methods, rendering it an appropriate tool for this systematic review. Further, it has been validated and reliably tested in the literature.<sup>23</sup>

## Results

The initial search yielded 1507 papers of which 46 were included in the final analysis ([figure 1](#)). Of these, 38 (83%) were conducted in the US, 3 (7%) in the UK, 3 (7%) in France, 1 (2%) in New Zealand and 1 (2%) in Italy. Forty-three (93%) were written in English and 3 (7%) in French.

Among the 46 studies evaluated, 6 were qualitative, 4 used mixed-methodology and 36 were quantitative (8 randomized control trials, 16 non-randomized control studies and 12 quantitative descriptive studies).

Seven categories of interventions emerged divided into two main health equity domains: healthcare (Interventions 1–4) and health education (Interventions 5–7):

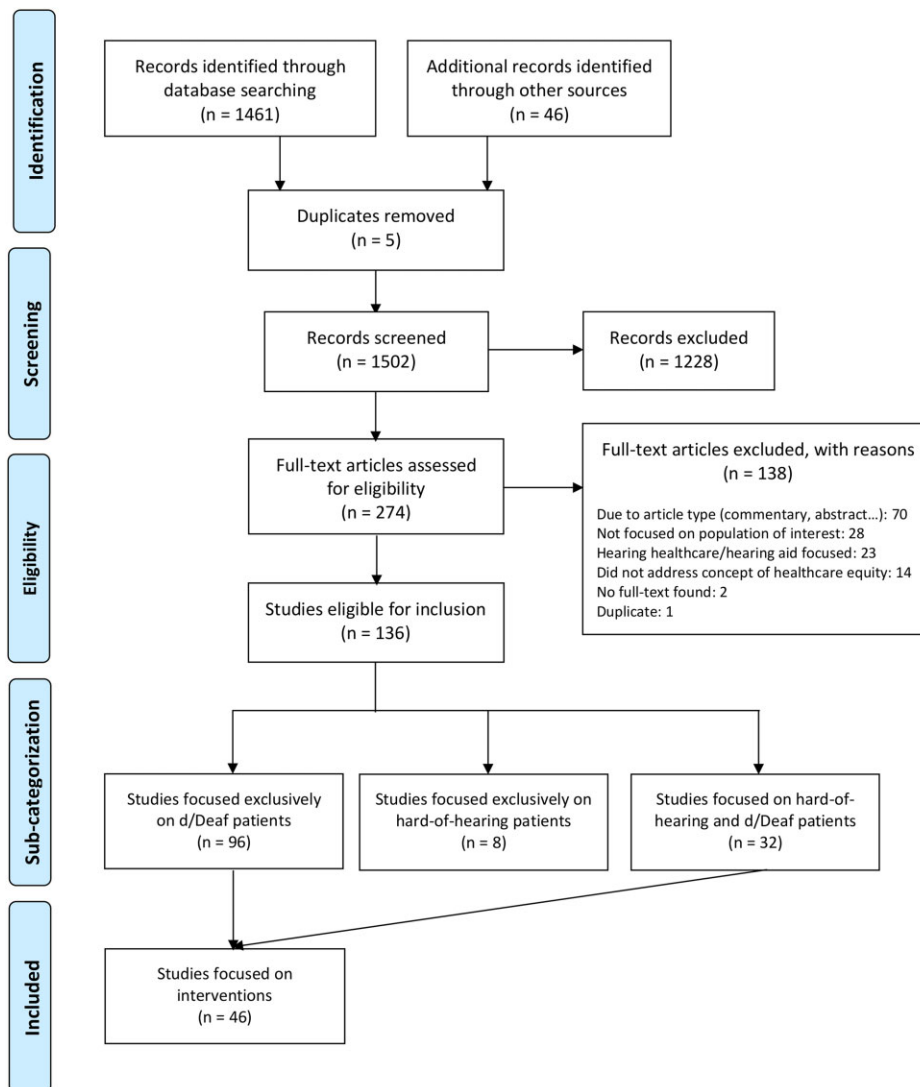
- (1) Use of Sign language during care, (2) Translation, validation and identification of clinical tools and scales, (3) Healthcare provider training program, (4) Development of adapted healthcare facilities, (5) Online interventions, (6) Educational programs and (7) Educational videos.

[Table 1](#) summarizes the main characteristics and risk of bias assessment of the studies analyzed in this systematic review. (See [Supplementary table S1](#) for detailed description of the studies and [Supplementary table S2](#) for the full risk of bias assessment.)

### Interventions addressing healthcare inequities

#### Intervention 1: Use of Sign Language during care

Access to professional Sign Language interpreters or to care providers who are fluent in Sign Language (i.e. Language concordant) appears to be an essential factor in achieving equitable care for d/Deaf people. In a cross-sectional survey published in 2010, the authors found that 43% of d/Deaf respondents preferred to have a direct consultation with a Sign Language fluent health professional and 50% preferred the presence of a Sign Language interpreter.<sup>24</sup> One study found that when Sign Language interpretation was not available during medical consultations, d/Deaf smokers or former smokers were at increased risk of poorer health outcomes.<sup>25</sup> Further, poor access to Sign Language interpreters has been associated with lower self-reported quality of life amongst d/Deaf patients proficient in Sign Language.<sup>9</sup> When language concordance between caregivers and d/Deaf patients is available (such that a Sign Language interpreter is not needed), it has been associated with



**Figure 1** PRISMA Flow diagram

higher appropriate use of preventive health services such as influenza vaccination amongst d/Deaf patients.<sup>26</sup> However, access to professional interpreters or language concordant care providers alone is not sufficient to achieve equitable care, most notably for those that identify as being a member of the Deaf community. For this group of d/Deaf patients, it also appears essential for healthcare providers to have an awareness of Deaf culture.<sup>27</sup> For example, the presence of an interpreter did not increase the willingness of d/Deaf LGBTI+ patients to communicate information about their health to their care providers.<sup>28</sup> Cultural sensitivity and providing non-judgemental care were also quoted as key factors for further reducing communication barriers.

Moreover, five studies analyzed the use of telemedicine with d/Deaf patients, with a predominant focus on its use in mental health.<sup>29–33</sup> These studies highlighted the usefulness of telemedicine in improving access to care for d/Deaf people. Indeed, the availability of Sign Language interpreters or Sign Language fluent care providers who speak sign language is sometimes very limited, particularly in rural areas. Telemedicine therefore could be useful by making it possible to carry out consultations remotely (see [table 1](#)).

### Intervention 2: Translation, validation and identification of clinical tools and scales

This review identified eight studies that have translated and/or validated or identified diverse clinical tools in Sign Language to better

assess the health issues impacting d/Deaf people, particularly in the field of mental and behavioural health and pain management (see [table 1](#)).<sup>34–41</sup>

Moreover, a qualitative study concerning prescription comprehension amongst Deaf patients suggested adaptations to improve prescription comprehension for d/Deaf patients, including verifying comprehension with the patient, replacing duration with specific dates and using visual aids (i.e. calendars/tables/drawings).<sup>41</sup>

### Intervention 3: Healthcare providers training program

Two studies looked at educating healthcare professionals on the unique healthcare needs and barriers faced by d/Deaf people.<sup>42,43</sup> The first study analyses a 2-year program dedicated to training medical students by teaching them Sign Language and exposing them to the Deaf community during a summer term.<sup>42</sup> The second is an analysis of a reverse role-playing activity for pharmacy students where they play the role of patients in a fictitious hospital where all the staff are deaf and only speak American Sign Language.<sup>43</sup>

Although very distinct, these two studies highlighted the importance of training healthcare staff in d/Deaf culture and improving their awareness of barriers issues when aiming to provide optimal care for d/Deaf people. In addition, both studies highlighted the relevance of using innovative pedagogical techniques to improve awareness of the linguistic and culturally distinct needs of d/Deaf patients when accessing healthcare.

**Table 1** Characteristics of the included studies, classified by type of interventions

Author, country, year of publication	Sample size	Study design	Key messages	Bias assessment (MMAT)
<b>Healthcare</b>				
<b>Intervention 1 Use of Sign Language during clinical care and telehealth</b>				
Henning, NZ, 2011	<i>n</i> = 68	Cross-sectional	Low access to and use of SLI adversely impact QOL	Fair
Middleton, UK, 2010	<i>n</i> = 999	Cross-sectional	Communication preferences could be met by increasing deaf awareness training for HCPs, a greater provision of SLI and of SL-fluent HCPs	Fair
Kushalnagar, US, 2018	<i>n</i> = 188	Cross-sectional,	d/Deaf smokers are at risk for poorer health outcomes if they do not have accessible communication with their HCPs through SLI or via ASL fluent HCPs.	Good
McKee, US, 2011	<i>n</i> = 89	Cross-sectional	Language-concordant patient-provider communication is associated with higher appropriate use of preventative services by deaf ASL users.	Good
Young, UK, 2016	<i>n</i> = 26	Qualitative	Linguistic access is necessary but not sufficient for promoting understanding—culturally coherent means of engagement are also required.	Good
Miller, US, 2019	<i>n</i> = 313	Cross-sectional	The presence of SLI does not promote or inhibit Deaf LGBTQ willingness to share health issues with HCPs.	Good
Austen, US, 2006	<i>n</i> = 134	Cross-sectional	Deaf staff were not more confident than hearing staff in using videoconferencing, but they were in using videophones, both professionally and personally.	Fair
Crowe, US, 2016	<i>n</i> = 24	Pre-post	TMH is a way to improve healthcare provision for less prevalent conditions in obscure regions.	Poor
Gournaris, US, 2004	<i>n</i> = 40	RCT	Findings support the use of video technology for d/Deaf ASL users.	Fair
Wilson, US, 2015	<i>n</i> = 95	Pre-post	Results suggest that the online program was as effective as residential programs in reducing alcohol use.	Fair
Crowe, US, 2017	<i>n</i> = 422	Cross-sectional	Deaf individuals are open to receiving TMH services and they may be a viable alternative to face-to-face psychotherapy, especially in the absence of accessible and available services.	Poor
<b>Intervention 2 Translation and/or validation of clinical tools and scales</b>				
McKee, US, 2015	<i>n</i> = 405	Mix-methods	The data suggest that the ASL-NVS is a useful health literacy instrument for Deaf ASL users.	Good
Samady, US, 2008	<i>n</i> = 10	Qualitative	The MHLC-ASL presents the MHLC items in ASL in an identical manner every time it is administered	Good
Athale, US, 2010	<i>n</i> = 311	Validation	Results suggest that the MHLC scales were successfully translated into an ASL version that can be used by the American Deaf community.	Poor
Guthmann, US, 2012	<i>n</i> = 198	Validation	The SAS-ASL provides a standardized Substance Use Disorder (SUD) screening for the deaf population demonstrating high sensitivity and good specificity	Fair
Pertz, US, 2018	<i>n</i> = 12	Qualitative	The ASL-PHQ and ASL-GAD now present the PHQ and GAD items in ASL.	Good
Guthmann, US, 2017	<i>n</i> = 30	Qualitative	Translation in ASL of six clinical or screening tools to assess alcohol or drug use disorder and mental health.	Good
Palese, Italy, 2011	<i>n</i> = 26	Qualitative	Within the limits of the study, it seems that d/Deaf patients prefer the IPT scale.	Good
Coignard, FR, 2015	<i>n</i> = 26	Qualitative	Lack of comprehension of prescriptions is common in d/Deaf patients. Adaptations can be made to prescriptions to improve comprehension and reduce medical error.	Good
<b>Intervention 3 Healthcare providers education program</b>				
Hoang, US, 2011	<i>n</i> = 364	Cross-sectional	Training medical studies in deaf cultural competency can significantly increase their capacity to care for Deaf community members and reduce health inequities	Poor
Mathews, US, 2011	( <i>n</i> = 70)	Role-reversal	Role-reversal exercise was an effective method of teaching students that the delivery of health care is dependent on adequate communication between health care provider and patient.	Poor
<b>Intervention 4 Development of adapted health care facilities</b>				
Equy, FR, 2012	<i>n</i> = 22	Case study	Description of a deaf-adapted services in an obstetrics and gynaecology clinic in Grenoble using SLI and training a small group of HCPs in FSL.	Poor
Amoros, FR, 2014	<i>n</i> = 116	Case study	This study describes epidemiological data regarding the care of d/Deaf people at a dedicated clinic and the benefits of this ambulatory system.	Poor
Pertz, US, 2018	<i>n</i> = 50	Pre-post	An integrated program with language and cultural concordant care could be a model for other centres.	Fair

(continued)

Table 1 Continued

Author, country, year of publication	Sample size	Study design	Key messages	Bias assessment (MMAT)
Health education				
Intervention 5 Online/e-health interventions				
Ryan, US, 2018	n = 515	Cross-sectional	Using eHealth platforms for social health engagement demonstrates potential to reduce health inequities among d/Deaf people	Good
Jones, US, 2010	n = 19	Qualitative	Evaluations of the web site were positive with strong preferences by Deaf users for interactive and visual aspects of the site.	Good
Kushalnagar, US, 2018	n = 74	Pre-post	Simplified breast cancer information is especially helpful for d/Deaf readers.	Fair
Palmer, US, 2017	n = 150	RCT	Bilingual approach (ASL and English) provides a better opportunity for lower educated Deaf ASL-users to access cancer genetics information than a monolingual approach.	Good
Kushalnagar, US, 2015	n = 32	Mixed methods	The results of this study suggest that simply making a health website accessible in ASL is not enough. It must also be user-friendly and easy to navigate.	Poor
Wilson, US, 2009	n = 55	Pre-post	Findings support continued research in the use of telehealth with d/Deaf population. Results show that such interventions can be used as an adjustment to communicating health-related information.	Fair
Intervention 6 Educational programs				
Jones, US, 2005	n = 123	Mixed methods	This community analysis led to the development of a heart-health education intervention which is being pilot tested using a quasi-experimental two-group study design.	Poor
Jones, US, 2007	n = 84	Pre-post	The program was effective in increasing culturally Deaf adults self-efficacy for targeted health behaviours related to modifiable cardiovascular diseases risk factors.	Poor
Patel, UK, 2011	n = 42	Pilot study	Results showed that the short-term impact of cardiovascular diseases risk assessment and associated health promotion in this group of d/Deaf patients did not reduce coronary heart disease risk estimates.	Poor
Sadler, US, 2001	n = 123	Mixed methods	The low adherence with breast cancer screening guidelines and the need for more knowledge highlight the importance of creating Deaf adapted health education programs.	Good
Intervention 7 Educational videos				
Choe, US, 2009	n = 130	RCT	This culturally aligned, educational video in ASL was shown to be an effective strategy for increasing and maintaining cervical cancer knowledge among deaf women.	Fair
Cumberland, US, 2018	n = 209	RCT	Breast cancer knowledge and screening practices are incomplete and inadequate in d/Deaf women, particularly those with lower levels of education.	Fair
Folkins, US, 2005	n = 102	Pre-post	ASL videos provide an effective tool for bringing cancer information to the Deaf community.	Fair
Engelberg, US, 2017	n = 62	Pre-post	Participants had significant improvement in their health knowledge. They also reported an increased motivation to seek more information and to share it with others.	Fair
Harry, US, 2012	n = 136	RCT	The study's findings support the value of producing culturally adapted and linguistically aligned videos for the Deaf community.	Fair
Hickey, US, 2013	n = 122	Pre-post	Breast cancer knowledge of d/Deaf women increased significantly by viewing an educational video in ASL and most of the new knowledge remained at the 2-month follow-up	Fair
Jensen, US, 2013	n = 107	Pre-post	The ovarian cancer education video offers an effective method to increase ovarian and general cancer knowledge for Deaf and hearing women.	Fair
Kaskowitz, US, 2006	n = 121	Mixed methods	Cancer education programs offered in ASL can help address health knowledge inequities.	Poor
Sacks, US, 2013	n = 175	Pre-post	Graphically enriched testicular cancer education video in ASL with English open captioning and voice overlay is an effective strategy.	Fair
Shabaik, US, 2010	n = 144	RCT	These results cumulatively provide support that the ASL-based colorectal cancer education intervention did increase knowledge.	Fair
Wang, US, 2010	n = 130	RCT	MHLC-ASL did not predict baseline knowledge or knowledge acquisition or retention for Deaf women who viewed a cervical cancer educational video.	Fair

(continued)



Table 1 Continued

Author, country, year of publication	Sample size	Study design	Key messages	Bias assessment (MMAT)
Yao, US, 2012	$n = 233$	Pre-post	Results suggest that although there may be a disparity in cervical cancer knowledge for the d/Deaf, there is a large benefit in disseminating linguistically accessible information.	Fair
Zazove, 2012, US	$n = 195$	RCT	No significant difference of adding an ASL interpreter and low-literacy captions on an existing English-speaking cancer prevention video on d/Deaf persons' understanding.	Good

MMAT, Mixed Methods Appraisal Tool, a critical tool for the appraisal stage of systematic mixed studies reviews; SLI, Sign Language interpreters; QOL, quality of life; HCPs, health care providers; RCT, randomized controlled trial; NVS, Newest Vital Sign, an instrument assessing health literacy based on a person's ability to answer six questions about a nutrition label; MHLC, Multidimensional Health Locus of Control, one of the most commonly used parameters of health belief in planning health education programs. This scale assesses the degree to which individual believe that his or her behaviour is controlled by external or internal factors; PHQ, Patient Health Questionnaire, a widely used questionnaire (nine items) to assess depression; GAD, Generalized Anxiety Disorder, a widely used questionnaire (seven items) to assess anxiety; IPT, Iowa Pain Thermometer, a self-reported intensity pain tool.

#### Intervention 4: Development of adapted healthcare facilities

Three studies described efforts that have gone a step further in providing equitable access to care for d/Deaf people by providing integrative models of clinical care specifically designed for this distinct patient population.<sup>38,44,45</sup> One study described the creation of deaf-adapted services in an obstetrics and gynaecology clinic in Grenoble, France.<sup>44</sup> The study showed adaptations to both outpatient and inpatient care of d/Deaf patients. Adaptations included ensuring all care providers were fluent in Sign Language, care coordination between clinic staff and in-hospital care providers during admissions and ensuring barrier-free access to in-hospital Sign Language interpretation services. However, it was found that adaptations were less effective in emergency situations (i.e. in the Emergency Department).<sup>44</sup> Similarly, a case study described an ambulatory consultation service in France devoted to primary care for d/Deaf people, highlighting the relevance of such services.<sup>45</sup> One key limitation of this article was that it was purely descriptive, lacking a formal evaluation of access or health outcomes related to their innovative care model.

Lastly, an American research team demonstrated the relevance of the creation of a Deaf Mental Health Clinic (based on an integrated healthcare model) to reduce depression and anxiety among d/Deaf patients.<sup>38</sup>

#### Interventions addressing inequities in health education

##### Intervention 5: Online/e-Health interventions

Six studies were identified that describe online interventions aimed at improving dissemination and comprehension of medical and health information to d/Deaf individuals.<sup>46–51</sup> All six studies found a positive effect of electronic media (website-based) when translated into Sign Language. Kushalnagar and colleagues found, however, that a simple translation was not sufficient to reach d/Deaf people effectively.<sup>50</sup> They concluded that there was a need to develop user-friendly health websites that take into account the lower health literacy of the target audience such as easy to understand video contents and usability testing experience and feedback during the design process.<sup>50</sup> Similarly, another study highlighted strong preferences for interactive and visual aspects of websites (such as graphics and animations) amongst d/Deaf users.<sup>47</sup>

##### Intervention 6: Educational programs

Given the barriers d/Deaf people face in accessing medical information and public health messages, specific health-focused educational programs for d/Deaf people have been developed.<sup>11,52–54</sup> A study by Jones *et al.* seems particularly interesting. Their research team first conducted a comprehensive community assessment of the health education priorities amongst d/Deaf adults. This revealed that learning about the cardiovascular disease was their main priority.<sup>11</sup> Based on these findings they created and evaluated an 8-week educational program (the Deaf Heart Health Intervention). It consists of a 16 h highly interactive class entirely in American Sign Language done by a trained deaf teacher. Its health content draws heavily from recommendations from the American Heart Association for primary prevention of cardiovascular diseases and found a statistically significant improvement in participants knowledge across different domains of cardiovascular health between baseline and 6-months post-intervention.<sup>52</sup>

In contrast, the pilot project of Patel *et al.*,<sup>53</sup> also based on a cardiovascular health promotion program for d/Deaf people, did not show any significant short-term improvement, which the authors attribute to enrolling a small, non-representative sample of patients.

Lastly, a study by Sadler *et al.* focused on addressing low baseline knowledge and adherence to breast cancer screening guidelines amongst a cohort of d/Deaf women in Southern California by implementing an in-person breast cancer prevention program using focus groups offered in ALS. Following this intervention, they found a statistically significant improvement in almost all knowledge domains analyzed amongst participants compared to their baseline pre-intervention knowledge.<sup>54</sup>

##### Intervention 7: Educational videos

Thirteen studies were identified that focus on improving access to health information and health education for d/Deaf people through culturally and linguistically adapted educational videos.<sup>55–67</sup> These videos all focused on improving knowledge around different forms of cancer (breast, cervical and testicular) across different domains (general health knowledge to cancer-specific knowledge) (see table 1).

All but one published study showed significant improvements in the general knowledge and cancer prevention knowledge in the d/Deaf population after viewing the videos of interest, at least in the short term (3–6 months). However, Zazove and colleagues did not show any further benefit of adding an ASL interpreter and low-literacy captions on an existing English-speaking cancer prevention information video.<sup>67</sup>

## Discussion

In recent years, a growing body of literature has focused on interventions aimed at improving equity in healthcare and health education for d/Deaf people. Our systematic review found seven different interventions to improve healthcare and health education equity for d/Deaf people (figure 2).

The results highlight the fundamental importance of access to community sign language interpreters to ensure healthcare equity for d/Deaf patients. Telemedicine can improve this access to overcome the lack of sign language interpreters in some rural or socio-economically disadvantaged areas. The average level of bias assessment of this intervention is fair. However, in the quasi absence of experimental comparative study design (one randomized controlled trial and one pre-post study), more evidence is needed to quantify the impact of this intervention.

In the absence of sign language interpreters, the adaptation of clinical assessment tools for d/Deaf patients appears to be a relevant, easily implementable and cost-effective intervention. These tools could compensate for the lack of community interpreters in certain situations (such as emergencies).

Moreover, increasing awareness amongst healthcare professionals of the issues involved in communicating with d/Deaf people, the barriers they face and improving their understanding of Deaf culture will provide skills for caregivers to better interact with these patients and probably improve healthcare equity. However, the scientific evidence for this intervention is relatively low. The number of studies and the poor average level of bias assessment of the article published do not allow a clear conclusion on the relevance of such an intervention. Research in this area needs to be strengthened.

Similarly, the descriptive design and the poor average level of bias assessment of the studies analyzing the development of adapted healthcare facilities (Intervention 4) do not allow any firm conclusion. Then, it appears to be costly and requires a medico-economic cost-effectiveness analysis to evaluate its feasibility. Pilot projects carried out in France and the USA should better assess this intervention in the coming years.

Linguistically and culturally adapted videos offer a valuable health education intervention. In addition, the development of training programs for d/Deaf people also appears to be a relevant intervention

for improving equity in health education. Still, the overall level of evidence is lower, and such an intervention seems less cost-effective.

The use of computer technology to develop websites or culturally and linguistically adapted software is also a relevant intervention to enhance access to health information and ultimately improve the health education of d/Deaf people.

Besides identifying seven categories of interventions, two main messages emerged from this literature review.

The first is that technology, when appropriately leveraged, can markedly improve communication between healthcare providers and d/Deaf patients, as illustrated by the numerous studies on e-health (including telehealth) and health education videos. Moreover, promising innovations are underway, such as artificial intelligence-based innovations for Sign Language interpretation into clinical care like KinTrans ([www.kintrans.com](http://www.kintrans.com)), SignAll ([www.signall.us](http://www.signall.us)) or the European SignSpeak project<sup>68</sup> and may help in the future to improve health equity for d/Deaf people.

The second message is that it is imperative to involve d/Deaf communities as active participants and meaningful contributors into all steps of intervention design and implementation (from the conception of the intervention to its implementation and evaluation).<sup>51,52,56</sup>

Our systematic review has some limitations. First, populations included across analysed studies are heterogeneous (e.g. some included only those who identify as members of the Deaf community, whereas others mentioned Deaf Sign Language users who may or may not identify as members of the Deaf community). However, our initial focus was explicitly on d/Deaf people (we purposely excluded hard of hearing people), limiting the heterogeneity of the analysed population. Second, the literature is heavily US-focused (83% of identified studies were conducted in the USA) and therefore limits the transferability of the findings. This is probably due to well-established research groups specifically composed of d/Deaf researchers in the USA. Third, the quality and bias assessment highlighted some methodological issues concerning the selected studies. However, many of these methodological limitations are probably associated with the study population, which is too often overlooked in the medical literature (e.g. the small sample size). Finally, numerous articles were found that describe an intervention but did not conduct or report an empirical evaluation of its impact. We believe

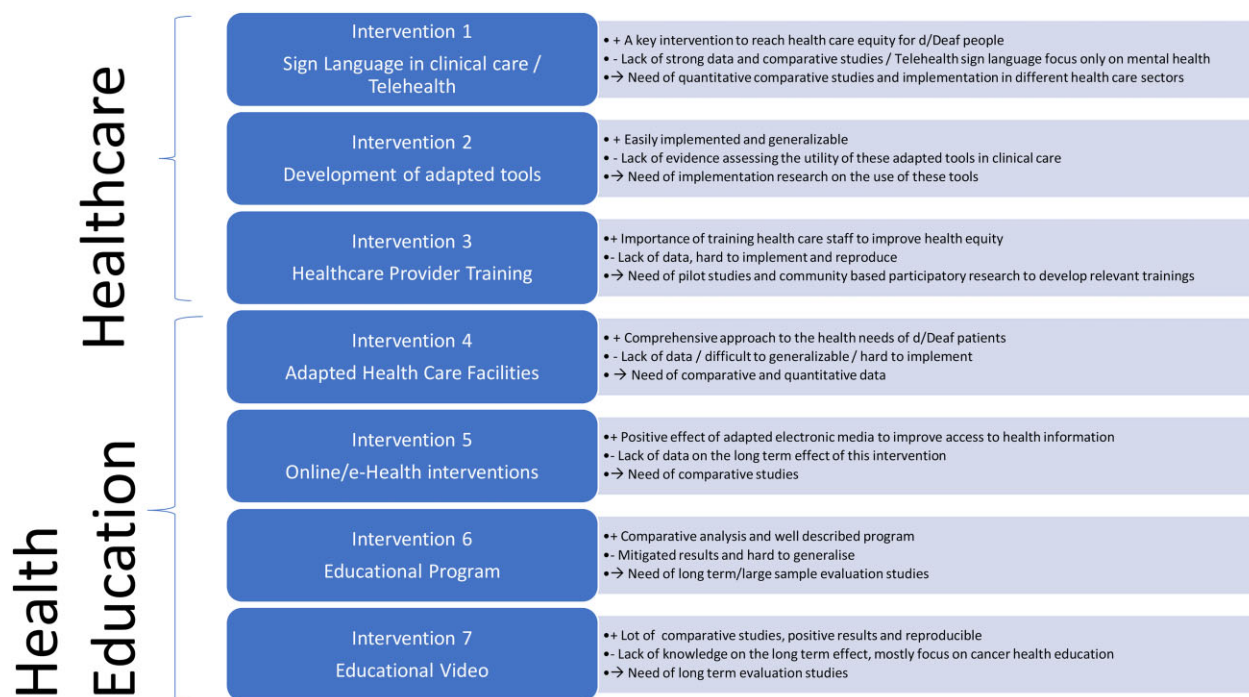


Figure 2 Synthesis of the results

there are likely many innovative interventions aimed at improving care for d/Deaf individuals worldwide. Conducting and publishing assessments of such interventions would add significant value to the current scientific literature and improve healthcare equity for d/Deaf individuals.

In the absence of one silver bullet, the way forward in improving health equity for d/Deaf people seems to be through the implementation and evaluations (including cost-effectiveness) of context-sensitive interventions in healthcare and health education. Moreover, the early involvement of members of the Deaf community and d/Deaf patients in the research and implementation process seems to be crucial. The search for health equity has involved innovation, curiosity and open-mindedness to adapt a practice or system by integrating all of these beneficiaries, as highlighted by the diversity of the literature concerning health equity for d/Deaf patients.

## Supplementary data

Supplementary data are available at *EURPUB* online.

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### Key points

- Many innovative interventions have been developed to improve equity in healthcare and health education for d/Deaf people.
- Technology and e-health play a fundamental role in tackling health inequities.
- Community-based participatory research will strengthen the success of new projects, their evaluation and implementation in close collaboration with the d/Deaf people.
- Strong evidence is still needed to better assess the effectiveness and the relevance of interventions aimed at reducing health inequities.

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