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## **Healthcare Needs of Deaf Signers: The Case for Culturally-competent Healthcare Professionals**

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47 **Abstract**

48

49 There is a need for culturally competent healthcare providers to provide care to deaf-signing  
50 patients who are members of a linguistic and cultural minority group with a distinctive physical  
51 constitution. Many deaf-signing patients have lower health literacy levels due to deprivation of  
52 incidental learning and inaccessibility to health-related material, increasing their risk for poorer  
53 health outcomes. Communication barriers arise because healthcare professionals are culturally  
54 ill-prepared to serve this population, with deaf signers reporting poor quality of interactions. This  
55 has translated to errors in diagnosis, patient nonadherence, and ineffective health information,  
56 resulting in mistrust of the healthcare system and patients' reluctance to seek treatment.

57 Available sign language interpreters have often not received in-depth medical training,  
58 compounding the dynamic process of medical interpreting. Healthcare professionals should  
59 thus become more culturally-competent, empowering them to provide cultural- and language-  
60 concordant services to deaf signers. Healthcare professionals who received training in cultural  
61 competency showed increased knowledge and confidence in interacting with deaf signers.  
62 Similarly, deaf signers reported more positive experiences when interacting with culturally-  
63 competent healthcare professionals. Cultural competency programmes within healthcare  
64 education remain inconsistent owing to the lack of instructional guidelines and institutional  
65 support. Caring for deafsigning patients is a complex, integrated competency requiring explicit  
66 attention and practice repeatedly in realistic, authentic learning tasks ordered from simple to  
67 complex. Attention to the needs of deaf signers can start early in the curriculum, using examples  
68 of deaf signers in lectures and case discussions, followed by explicit discussions of  
69 characteristics of Deaf cultural norms and potential risks of low written/spoken language

70 literacy. Students can subsequently engage in role plays with each other or representatives of the  
71 local deaf-signing community. This will ensure that future healthcare professionals are equipped  
72 with necessary skills required to provide appropriate care and ensure equitable healthcare access  
73 for deaf-signing patients.

74

75

76 Approximately 70 million people worldwide are deaf and use a sign language.<sup>1</sup> They consider  
77 themselves to be members of a linguistic and cultural minority group, as they identify with other  
78 deaf signers based on shared experiences of using sign language, being a part of a signing deaf  
79 community, and adopting deaf cultural norms. While the conventional “uppercase D” Deaf has  
80 also been used to describe their cultural identity, we refer to deaf signers in this paper as we  
81 recognize that Deaf people may rely on other communication modalities (e.g. lip-reading)  
82 despite sign language being their preferred language. Thus, in this context, we will be focusing  
83 on situations and scenarios in which deaf people use sign language. To deaf signers they are not  
84 disabled in terms of the medical model of deafness as their condition is not an impediment and  
85 they don’t have a hearing ‘loss’ but a hearing ‘difference’.<sup>2</sup> The World Federation of the Deaf  
86 asserts that signing deaf communities need linguistic rights , highlighting a critical need for them  
87 to receive and give information using a language of their choice (usually their national sign  
88 language) in all contexts including official interactions. Failure to do so not only violates their  
89 linguistic rights but perpetuates the exclusion of deaf signers in society.<sup>3</sup>

90

91 In this paper, we the authors will highlight the healthcare-related challenges faced by deaf  
92 signers, then highlight the gaps in and importance of culturally-competent healthcare

93 professionals, and finally suggest steps that can be taken to embed cultural competence education  
94 within healthcare education.

95

## 96 **Literacy Levels**

97 Those who are hearing-abled learn and develop their knowledge of the word and the world from  
98 observing and listening to conversations around them.<sup>4</sup> Deaf signers are thus deprived of these  
99 incidental learning opportunities as health information delivered via radio and television  
100 commercials, and even overheard conversations of family members' medical histories are not  
101 accessible.<sup>5-7</sup> Deaf signers also communicate using a visual language which is unavailable in  
102 written format, thereby posing a challenge when it comes to reading health education material.<sup>8,9</sup>  
103 This is further compounded by the fact that only a limited amount of health resources are  
104 available in sign language,<sup>10</sup> while the available material is frequently higher than the  
105 recommended sixth-grade reading level.<sup>11</sup> These factors have led to lower health literacy levels  
106 in deaf signers compared to their hearing counterparts with the same level of formal education.<sup>10</sup>  
107 An example is the lower knowledge of health preventative strategies for cancer in this population  
108 in the US.<sup>12</sup> Additionally, in face-to-face interviews with 203 deaf signers in the US to assess  
109 their knowledge on cardiovascular risks, 40% and 60% of respondents failed to list any  
110 symptoms of a heart attack and stroke, respectively. This places them at a higher risk for health  
111 problems,<sup>5</sup> and results in lower health status and poorer health outcomes compared to the general  
112 population.<sup>13</sup>

113

114 Due to the barriers to acquiring these secondary learning opportunities, deaf signers also have

115 low literacy levels in spoken/written language(s) such as English.<sup>5</sup> Indeed, a phenomenological  
116 study involving deaf signing patients in Australia found that due to the lower proficiency in  
117 English as well as the lack of health information available in Auslan (Australian Sign Language),  
118 patients faced significant barriers in accessing health information. It was also noted that in  
119 instances where information was provided to them in English, they were unable to understand it  
120 clearly.<sup>14</sup> This issue is further compounded by the commonly held misconceptions that deaf  
121 signers can communicate in the local spoken/written language, and that sign language is simply a  
122 gestured representation of the local language; which it is not. In fact, sign language differs  
123 significantly from a spoken language as it is a complex visual-spatial language of its own and it  
124 contains unique syntax and grammatical structures. Together, there are over 300 different types  
125 of sign languages across the globe;<sup>1</sup> all of which are informed and influenced by local cultural  
126 and geographic situations.<sup>15</sup>

127

## 128 **Barriers in communication with healthcare professionals**

129 Members of signing deaf communities face communication barriers with healthcare providers  
130 (HCPs), which contribute to lower health literacy levels and limits access to adequate  
131 healthcare.<sup>9,11,16</sup> In addition, misdiagnosis, delayed treatment, unnecessary testing, and privacy  
132 breaches are not uncommon amongst signing deaf patients,<sup>16,17</sup> with reports from Australia  
133 showing less than 30% of health conditions in this population being diagnosed and treated  
134 properly.<sup>18</sup> In the US, HCPs were perceived as treating signing deaf patients in a paternalistic  
135 manner with treatment provided without patients' full understanding of their health condition or  
136 improper informed consent, resulting in nonadherence and compromising the patient's right to  
137 autonomy.<sup>16</sup> In addition, very few patients in the US reported that they were given information

138 by HCPs on preventive healthcare practices, highlighting gaps in patient education which were,  
139 again, most likely due to communication barriers.<sup>12,16</sup>  
140  
141 Undesirable past experiences with HCPs and their unwillingness to understand signing deaf  
142 patients' needs has fostered distrust, discouraged signing deaf patients from seeking future  
143 medical care, and led to reports of lower satisfaction with their HCPs.<sup>9,17,19,20</sup> This was  
144 illustrated in a study in Italy exploring the perspectives of hospitalized signing deaf patients that  
145 revealed vulnerability, discomfort, lack of consonance between care and needs, and  
146 disempowerment.<sup>21</sup> In the US, HCPs themselves expressed that they felt uncomfortable around  
147 signing deaf patients and believed that deaf signers did not trust them,<sup>20</sup> while in Malaysia, HCPs  
148 found interacting with signing deaf patients too time-consuming.<sup>6</sup> It has thus been stressed that  
149 as long as communication barriers are not addressed, health inequalities faced by signing deaf  
150 patients will continue to worsen.<sup>19</sup>

151  
152 There is a growing number of deaf and hard-of-hearing people who have qualified as HCPs in  
153 recent years,<sup>22,23</sup> partly due to advancements in technologies such as amplified stethoscopes and  
154 various legislative changes.<sup>22</sup> These groups of HCPs with language concordant patient-provider  
155 communication, are likely to communicate more effectively with deaf patients, positively  
156 impacting patients' adherence to treatment and recall of medical instructions,<sup>23</sup> and indeed deaf  
157 signing patients have responded positively to the use of HCPs with sign language skills.<sup>9</sup> The  
158 number of deaf signing HCPs are, however, still low.

159  
160 **Sign language interpreter-mediated healthcare**

161 Sign language interpreters are trained to work in a wide range of public service settings and are  
162 bound by a code of ethical conduct whereby they are expected to remain impartial and their  
163 presence is only to mediate the communication between parties.<sup>24</sup> In most countries there is a  
164 distinct lack of systematic in-depth medical training for sign language interpreters. That which is  
165 available tends to be ad hoc and not necessarily embedded in formal training curricula (e.g. in  
166 universities). There are established best practices in the US for training healthcare interpreters  
167 as medical specialists alongside deaf HCPs,<sup>25</sup> but training standards are inconsistent depending  
168 on the country.<sup>26</sup>

169  
170 HCPs and deaf patients do not typically share the same language, so interpreters have to mediate  
171 the communication, which can lead to a range of issues. Because of the lack of consistent  
172 medical training for interpreters, achieving accuracy of interpretation in healthcare can be a  
173 challenge. Interpreters will often be faced with unfamiliar concepts, and may not have a full  
174 understanding of healthcare terminology if they have not had appropriate training.<sup>27</sup> There are  
175 also risks because there is often a lack of an equivalent medical vocabulary in sign language.  
176 Thus, it is difficult for sign language interpreters to prepare for healthcare interpreting  
177 assignments, as they cannot always predict the direction that a healthcare consultation will take.  
178 The success of interpreter-mediated healthcare interaction depends significantly on the linguistic  
179 choices made by interpreters,<sup>28</sup> and untrained interpreters may inappropriately omit or alter  
180 important health information.<sup>29</sup> The success of the consultation also relies on HCPs and patients  
181 understanding the role of the interpreter.<sup>30,31</sup> Even when healthcare interpreting services are  
182 available with professionally-trained and qualified interpreters, deaf signers in various countries  
183 still report barriers to accessing healthcare information.<sup>28,32,33</sup> In this potentially high

184 consequence setting, “*an incorrect explanation of symptoms to the practitioner or incomplete*  
185 *instructions to the patient can have serious ramifications: the wrong diagnosis or treatment can*  
186 *be life threatening*”.<sup>34</sup> So it is important that interpreters seek clarification from HCPs while  
187 interpreting if they do not understand, in order to ensure that medical information is accurately  
188 conveyed and to support the relationship between the HCP and deaf patient.<sup>35,36</sup>

189  
190 Thus, despite the importance of training medical interpreters, it is imperative that HCPs do not  
191 solely rely on interpreters to mediate interactions with their patients. HCPs themselves should be  
192 prepared to provide the best care for their deaf patients by understanding Deaf culture and even  
193 better providing direct language concordant services.<sup>37</sup>

194

195

## 196 **Cultural competency**

### 197 **Culturally-incompetent healthcare practices**

198 Cultural competency in healthcare has been identified as an important approach to reducing  
199 health disparities. It is defined as, “*a set of congruent behaviors, knowledge, attitudes, and*  
200 *policies [...] that enables effective work in cross-cultural situations.*”<sup>38</sup> The concept of cultural  
201 competence has been critiqued and replaced by terms such as critical consciousness<sup>39</sup> or cultural  
202 humility,<sup>40</sup> which stress that there is no end point of ‘being competent’ and that HCPs need to  
203 engage in a lifelong process of critical self-awareness and critical reflection in cooperation with  
204 patients, communities, and colleagues, bringing into check the power imbalances between HCPs  
205 and patients. Cultural competency remains, however, the most used terminology within  
206 education and hence, will be used throughout this paper while recognizing its limitations.<sup>41</sup>

207  
208 Culturally-incompetent healthcare practices continue to propagate health disparities in signing  
209 deaf communities, hindering holistic care in the medical setting.<sup>17</sup> Despite the existence of  
210 United Nations' goals and federal laws that mandate equal access and communication in all  
211 healthcare settings for deaf people, they continue to receive unequal health care.<sup>42</sup> In a recent  
212 Lancet review, Wilson et al<sup>43</sup> highlighted HCPs' poor communication skills and lack of  
213 understanding of deaf cultural norms of as contributory factors to the barriers faced by deaf  
214 signers to healthcare. Many HCPs are, indeed, unaware of the fact that deaf cultural norms,  
215 which are based on their visual orientation, is different.<sup>20</sup>  
216  
217 There is also a lack of awareness about deaf patients' linguistic rights, and the sociocultural  
218 aspects of deafness, as reported in countries such as the US, Malaysia, and Greece.<sup>17,20,44,45</sup> In  
219 addition, it is well documented that HCPs are generally unprepared to understand or serve the  
220 needs of signing deaf patients, as they lack the training to provide linguistically and culturally-  
221 competent care for them.<sup>5,9,19</sup> This will then hinder them from being able to accommodate the  
222 special requirements of signing deaf patients or provide effective healthcare to these patients.<sup>16</sup>  
223 Thus, it has been suggested that competency-based training for HCPs be made more accessible.<sup>43</sup>

224

### 225 **Cultural-competency as a tool for HCPs**

226 Cultural competence education has become more widespread as a result of a shift in  
227 demographics globally. While available literature initially focused on strategies to improve the  
228 quality of care across racial/ethnic groups,<sup>46,47</sup> cultural competence education has more recently  
229 expanded to include other marginalized populations such as the Lesbian, Gay, Bisexual and

230 Transgender (LGBT) community. Indeed, an educational intervention in a primary care clinic  
231 reported a significant increase in LGBT knowledge among nursing staff upon completing their  
232 cultural competence module.<sup>48</sup> Such benefits can be extended to deaf signing patients, who are  
233 also at risk for stigmatization and/or have differences in healthcare needs that puts them at higher  
234 risk of experiencing inequality in the care received.<sup>49</sup>

235  
236 There is evidence to suggest that deaf cultural-competency training for HCPs contributes towards  
237 better health service accessibility.<sup>11,16</sup> In a study comparing medical students trained in American  
238 Sign Language (ASL) and Deaf culture versus students who received no training, the former had  
239 significantly higher knowledge on Deaf culture. This also led to a better understanding of the  
240 challenges deaf signers face with the healthcare system that extends beyond their physiological  
241 differences (i.e. their inability to hear) such as fear of mistreatment by staff, limited health  
242 literacy, and the lack of awareness of medical terms. The authors postulated that this would  
243 translate to HCPs who are able to respond to the issues faced by deaf signers in a more effective  
244 manner, thereby reducing the healthcare disparities faced by them.<sup>20</sup> Osteopathic medical  
245 students who attended a workshop on ASL and Deaf culture also reported significantly higher  
246 knowledge and confidence levels in interacting with deaf signers.<sup>50</sup>

247 In a study exploring deaf signers' experiences in the healthcare system, positive experiences such  
248 as improved interactions, and being involved in the decision-making process, were related to the  
249 presence of medically-certified interpreters, HCPs with sign language skills, and practitioners  
250 who made an effort to improve communication.<sup>9</sup> Deaf signers' access to healthcare can be  
251 enhanced through modifying the knowledge, attitudes, and behaviors of HCPs,<sup>45</sup> but instilling  
252 cultural competence amongst HCPs is most effective if done at the early stages of HCP

253 education. Thus, educating healthcare students and incorporating curricula on cultural  
254 competence may bridge the gap between HCPs and signing deaf patients.

255

### 256 **Cultural-competency in health education**

257 In 2000, the Liaison Committee on Medical Education, which accredits US medical schools,  
258 introduced a new standard that emphasized the significance of incorporating cultural competency  
259 in the medical curricula.<sup>38</sup> While in the United Kingdom (UK), statements referring specifically  
260 to communication skills when serving populations who communicated differently due to a  
261 disability, were highlighted in the 2018 update of the UK Outcome of Graduates by the General  
262 Medical Council.<sup>51</sup> No mention, however, was made in reference to deaf populations  
263 specifically. Although there has been an effort by medical schools to adhere to these standards,  
264 cultural competency programmes often exclude aspects on signing deaf communities and  
265 cultural norms. This is illustrated in a recent review of medical school interventions on cultural  
266 competency, where only 10 out of 154 interventions addressed populations with disability  
267 identities and deaf culture.<sup>52</sup>

268

269 Pharmacy education institutions have also been slow in the uptake in cultural competency within  
270 the curricula with little mention of deaf interactions.<sup>13</sup> The American College of Clinical  
271 Pharmacy has also noted that attempts to incorporate elements of cultural competency into the  
272 curricula have been inconsistent and limited.<sup>53</sup> These inconsistencies in healthcare education are  
273 attributed to the lack of explicit instructional guidelines for cultural competence curricula and the  
274 insufficient commitment from institutions.<sup>13,52</sup> In addition, cultural competency programmes  
275 have commonly adopted the “categorical approach” which meant teaching about the specific

276 values, beliefs and behaviors of certain cultural groups.<sup>54</sup> However, it's drawback is the risk of  
277 oversimplifying cultures and misrepresenting their issues as one-dimensional and stereotypical.<sup>52</sup>  
278 Hence, cultural competency curricula should progress to adopt the "cross-cultural" approach  
279 which takes into account the sociocultural aspects which might influence the patient's care.<sup>54</sup>

280

## 281 **Implications for education**

282 In this perspective, we the authors have sought to highlight the importance of preparing HCPs for  
283 caring for signing deaf patients. But how should we approach this? Instructional design models  
284 generally start with a needs analysis to uncover what students should learn and a design phase to  
285 systematically plan how they can learn this best. It is important to involve all stakeholders in the  
286 needs analysis,<sup>55</sup> which in this case would mean involving not only teachers, but also students,  
287 working HCPs, as well as representatives of signing deaf communities.

288

289 Which competencies do HCPs need to care for signing deaf patients? In this perspective, we  
290 point out that HCPs need to be aware of the potential lower health literacy of deaf-signing  
291 patients and the underlying reasons for it, such as a low literacy in spoken/written languages and  
292 lack of access to healthcare information in sign language. However, HCPs will also need to have  
293 adequate skills to detect that patients are deaf and acquire the necessary skills to communicate  
294 with them. Pendergrass suggests teaching key phrases to facilitate initiation of a visit and explore  
295 the deaf signer's communication preference.<sup>56</sup> The exact competencies that students need to  
296 acquire may also vary based on local needs, depending for example on the health care system,  
297 division of tasks between different HCPs, or the availability of interpreters.

298

299 Caring adequately for deaf-signing patients is a complex, integrated competency that requires  
300 explicit attention and practice repeatedly in realistic, authentic learning tasks ordered from  
301 simple to complex.<sup>57</sup> This aligns with modern learning theories<sup>58</sup> that stress the importance of  
302 applying knowledge in authentic situations, similar to what students will encounter in their  
303 professional life in order to make sure that students will be able to transfer what they learn to  
304 practice. Attention for caring for deaf patients can be part of larger educational interventions  
305 focused on developing cultural competency and skills to communicate with groups experiencing  
306 health disparities. We would argue that this should be integrated in the whole curriculum, and  
307 not only in a separate (elective) course, because this allows students to learn the required  
308 competencies in all relevant contexts and also makes clear that caring for groups experiencing  
309 health disparities is part of normal care. Attention for the needs of signing deaf communities can  
310 start early on. Simply using examples of deaf-signing patients in some lectures or case  
311 discussions can alert students to the existence of deaf-signing patients and their specific needs.  
312 Subsequently, students will need to acquire knowledge about the characteristics of Deaf cultural  
313 norms and the potential risks of low written/spoken language literacy, for example in a  
314 discussion session around patient cases. Patient stories can provide insight, show relevance, and  
315 affect perspectives in subtle, but important ways.<sup>39</sup>

316  
317 The next step would be to learn how HCPs can communicate with and address the needs of deaf-  
318 signing patients. One way to get more insight in the role of HCP in this regard is to observe role  
319 models interacting with deaf-signing patients in the clinic (or videos thereof) <sup>40</sup>Thew et al  
320 propose role plays where students practice with a fellow student playing a deaf patient.<sup>59</sup> or with  
321 simulated patients (actors) who are part of the local deaf-signing community. Prendergrass

322 suggests that role reversals, i.e. students playing the role of deaf-signing patients, allow HCPs to  
323 personally experience barriers to communication, autonomy, and privacy.<sup>56</sup> Video-taping role  
324 plays or interactions with real deaf-signing patients in the clinic gives the opportunity to  
325 critically review one's own communication with deaf-signing patients.<sup>40</sup> In principle, this can  
326 also be part of regular assessment activities, as shown by Green et al. who included a case of a  
327 transgender patient in an Objective Structured Clinical Examination (OSCE).<sup>60</sup>

328

## 329 **Conclusions**

330 The healthcare disparities faced by deaf signers are exacerbated by the HCPs' ignorance about  
331 Deaf culture and the health-related challenges faced by this population such as lower health  
332 literacy levels and prior bad experience with HCPs. The interpretation process between sign  
333 language interpreters, HCPs and the deaf-signing patient is also a dynamic one, and one which is  
334 compounded by the lack of in-depth medical training received by interpreters. This makes a clear  
335 case for the need for HCPs themselves to be trained in cultural competency, which is currently  
336 lacking in healthcare education. Active-learning approaches would seem suitable to illuminate  
337 the challenges faced and train healthcare students on how to manage this subset of patients. This  
338 will then ensure deaf-signing patients have equitable access to healthcare services, and better  
339 health literacy levels, which will hopefully translate to lower morbidity levels. Future research  
340 should focus on evaluating best practices for treating deaf-signing patients, as well as effective  
341 educational methods for training healthcare students and/or HCPs in cultural competency.

342

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