Access to effective communication aids and services among American Sign Language users across North Carolina: Disparities and strategies to address them

Mark J. Myers, Izabela E. Annis, Jan Withers, Lee Williamson, Kathleen C. Thomas

Mark J. Myers, Department of Government and Public Affairs, Gallaudet University
Izabela E. Annis, Division of Pharmaceutical Outcomes and Policy, UNC Eshelman School of Pharmacy
Jan Withers, Division of Services for the Deaf and Hard of Hearing, NCDHHS
Lee Williamson, Division of Services for the Deaf and Hard of Hearing, NCDHHS
Kathleen C. Thomas, Division of Pharmaceutical Outcomes and Policy, UNC Eshelman School of Pharmacy; Division of Research, Mountain Area Health Education Center; Mental Health Services Research Program, UNC Cecil G. Sheps Center for Health Services Research

Corresponding author:
Kathleen C. Thomas
Kathleen_thomas@unc.edu

Author contributions: Mark J. Myers, who wrote the first draft of the article, participated in study design, analyzed and interpreted the qualitative data. Izabela Annis was responsible for quantitative data management, analyses, and interpretation. Lee Williamson participated in study design, recruitment and implementation of forums, recruitment for the online survey, creation of the online survey instrument including embedded video clips and reviewed the manuscript for completeness. Jan Withers originated the idea, participated in study design, and reviewed the manuscript for completeness. Kathleen Thomas participated in study design, interpretation of the quantitative data, and manuscript preparation.

Preliminary findings were presented at the NC Institute of Medicine, May 2019.
Access to effective communication aids and services among American Sign Language users across North Carolina: Disparities and strategies to address them

Abstract

Objective. To examine the extent to which communication aids and services used by American Sign Language (ASL) users and their healthcare providers aligns with preferences, satisfaction, and unmet needs; and to elicit from stakeholders strategies to address disparities.

Methods. A cross-sectional study was conducted of ASL users in North Carolina. Respondents completed an online survey presented in ASL and English (N=189). McNemar’s tests were used to compare rates of preferred and actual methods of communication. Logistic regression models explored relationships of accessible communication with dissatisfaction and unmet need. Qualitative interviews explored satisfaction with communication and reflections on what works, what does not, and outcomes (N=54).

Results. While 45% of respondents used a professional sign language interpreter, 65% of respondents preferred to do so. Accessible communication was associated with lower odds of dissatisfaction with communication (OR=.19, p<.05). Dissatisfaction with communication was associated with greater odds of unmet need for healthcare (OR=8.95, p<.05). Interview respondents emphasized their preference for on-site interpreters, explaining how video remote interpreting was subject to technical difficulties while writing back and forth led to important gaps in understanding.
Conclusions. While ASL users prefer to use professional, on-site sign language interpreters to communicate with providers, most use some other form of communication instead. Findings emphasize the need for policy strategies to facilitate access to high quality, well-functioning professional interpreter services and to have those services delivered on-site to overcome disparities.

Keywords: American Sign Language, health disparities, communication access
Introduction

American Sign Language: Prevalence and Americans with Disabilities Act Compliance

American Sign Language (ASL) is a unique language grammatically and syntactically distinct from English and sign languages in other English-speaking countries (Moreland et al., 2015; Singleton et al., 2004). The Centers for Disease Control report that there are 1.7% of infants in the US who are Deaf or Hard of hearing but note that estimates are imprecise due to inconsistent screening (CDC, 2020). Hearing loss may also occur later in life. The number of ASL users in the US remains uncertain, with estimates spanning a broad range from .03 to 5% (Mitchell, 2006).

The Americans with Disabilities Act (ADA, 1991) stipulates that ‘no individual with a disability is excluded, denied services, segregated or otherwise treated differently than other individuals because of the absence of auxiliary aids and services.’ Auxiliary aids and services for individuals who are Deaf or Hard of hearing are defined broadly to include, for example, qualified interpreters on-site or through video remote interpreting (VRI) services; exchange of written notes; or other effective methods of making aurally delivered information available. Programs must provide accommodation through appropriate auxiliary aids and services to ensure effective communication (ADA). Borrowing from the ADA wording for standards for building codes, these accommodations ensure accessible communication (ADA standards). While the ADA language echoes that of the field of health communication, it is important to note differences in meaning. The field recognizes barriers to access to healthcare (unmet need for services), and ineffective communication (lack of questions or shared decision-making) between patients and
providers. The ADA is concerned, elementally, with accessible communication (accommodation through aids and services) to ensure effective communication (in this context meaning equivalent to a hearing person’s; Withers & Speight, 2017). This paper examines aids and services to provide accessible communication and ASL user assessment of their effectiveness to support communication equivalent to a hearing person’s. By assessing user satisfaction with communication accessibility, the paper moves beyond delivery of information to encompass dyadic exchange.

Limited data undermine efforts to describe disparities in accessible communication

Deaf individuals’ preference for accessible communication strategies vary (McKee, Moreland et al., 2015), and healthcare providers remain unaware of Deaf individuals’ communication needs (Nonaka, 2016). Self-reported data is limited, but ASL interpreters judge that nearly all Deaf individuals rate on-site interpreter services as adequate, only half rate technology-based aids such as VRI as adequate, while fewer than half rate lip-reading and written notes as achieving adequate accessibility. In contrast, English-speaking providers rate all modes at about 80% adequate (Hommes et al, 2018). Qualitative work documents wide-spread lack of accessible communication aids and supports (McKee, Schlehofer et al., 2011; Steinberg et al., 2006).

Few healthcare providers in the US are fluent in ASL which is the ideal (less than 20 per year in the one institution with a focused training program; Hall et al., 2019). When Deaf individuals can use ASL directly with providers they are more likely to use preventive services McKee, Barnett et al., 2011). In the context of chronic disease management interventions, Deaf participants have described the importance of communicating about health topics with ASL directly in order to
form a mutual bond (Havercamp et al., 2020). Using ASL directly or through an interpreter is associated with increased rates of cancer screening communication (Kushalnagar et al., 2018), however an Idaho state review of ADA complaints indicates a lack of qualified interpreters (Schniedewind et al., 2020). A strategic national US convenience sample of Deaf individuals indicated that 43% had used VRI, and 59% of users found it unsatisfactory (Kushalnagar et al., 2019). Because ASL is not a spoken or written language, the grammar and syntax do not map onto English. An early US Government Accountability Office report indicates that only 40% of spoken English is visible on the lips for lip-readers (GAO, 1988). Similarly, the accessibility of writing notes back and forth is hindered by limited English proficiency and low health literacy among Deaf individuals (McKee, Paasche-Orlow et al., 2015; Singleton et al., 2004). At the same time, the literature continues to document ongoing disparities in health service use experienced by Deaf individuals (Kushalnagar et al., 2020; Ryan & Kushalnagar, 2018; Barnett et al., 2011; Iezzoni et al., 2004).

Due to the low prevalence of ASL use and emerging literature on quantitative measurement for health services research among Deaf individuals, community measures of preferred and actual modes of communication and their outcomes are limited (Kushalnagar et al., 2018; McKee, Paasche-Orlow et al., 2015; Mitchell, 2006). The objective of this paper is to address this gap for North Carolina through a mixed methods study exploring quantitative data on preferred and actual modes of communication and their outcomes, together with qualitative data exploring further nuances of communication accessibility. The study moves the field forward by using a mixed methods approach so that participant reflection can interpret quantitative findings, by creating and using an online survey with embedded video clips to achieve high quality
communication with ASL-using survey respondents, and by collecting nuanced information on communication preferences and barriers to accessibility (Withers & Speight, 2017). The study design is framed by the Behavioral Model of Healthcare Use, a widely used public health conceptual framework, where predisposing (sociodemographics), enabling (financial, skills, accommodations), and need (health status, conditions, severity) characteristics of an individual impact their healthcare use, satisfaction and health outcomes (Figure 1; Gelberg et al., 2000; Aday & Andersen, 1974). This study explores the hypothesis that communication accessibility is an enabling characteristic that affects communication dissatisfaction which in turn affects unmet need for care.

**Methods**

Our study team reflects Deaf community standards for engaged research (McKee et al., 2013). Dr. Myers’ and Ms. Withers’ primary language is ASL and they are also fluent in written English. Mr. Williamson is a child of Deaf adults whose first language is ASL and second English. Dr. Thomas is monolingual in English.

**Setting and Data Sources**

Study participants were individuals who use ASL as their primary language and who received services, newsletters, or worked for the North Carolina Department of Health and Human Services Division of Services for the Deaf and Hard of Hearing. In this manner, recruitment was accomplished through peer and trusted Deaf community partnerships (McKee, Thew et al., 2012; Barnett et al., 2011). An online survey fielded from May 2018 until March 2019 collected in-depth information about participants’ communication preferences, communication strategies,
patient information-seeking, satisfaction with communication and care, and demographics from a convenience sample of Division contacts (N=189). Survey items were translated by two bilingual translators: Dr. Myers and Mr. Williamson. Survey items were presented in English and ASL video clips (Figure 2).

Individual interviews were conducted at four community forums from June 2018 to February 2019 (N=54). The forums also provided educational programming and opportunity for socializing in accordance with standards for community-based participatory research with the Deaf community (McKee, Thew et al., 2012). Interviews were conducted by Dr. Myers in ASL in collaboration with Mr. Williamson who coordinated logistics (Anderson et al, 2018). All Deaf-blind participants had sufficient sight to be accommodated by narrowing the visual field of ASL communications. Interview questions elicited participants’ reflections regarding personal experiences of communication accessibility in health care settings. Initial prompts explored experiences and satisfaction: 1) What is your experience in communication with your doctors? Would you describe a typical experience? and 2) Were you satisfied? Why or why not?

Interviews were conducted in ASL by the lead author, videotaped and transliterated into text for data analysis immediately after conducting the interviews (DeNardo & Levers, 2002). Interview participants also completed the online survey. All participants provided informed consent to participate in compliance with the university Office of Human Research Ethics.

Survey Measures

Two outcomes were explored. Dissatisfaction with communication accessibility was captured by the question, “Are you satisfied with how you and your doctor/provider communicate?”
Responses were captured on a 3-item Likert scale from very satisfied to not satisfied. A dichotomous measure was modeled, dissatisfied (vs. very or somewhat satisfied). This question was designed based on communication satisfaction questions in the HINTS-ASL (Kushalnagar, 2017). Unmet need for care was captured by the question, “Did you get the health/mental health services you needed or requested?” with a yes/no answer.

Independent variables of interest were 1) preferred and 2) actual methods of communication with providers (Kushalnagar, 2017). Preferred communication method was identified by the question, “How do you prefer to communicate with your doctor or medical provider?” Actual communication method was captured by the question, “How does your doctor/provider communicate with you?” Options were direct sign language or cued speech, professional sign language interpreter, layperson interpreter (such as family, friend or practice staff), lip-reading/speaking (where the Deaf person relies on lip-reading to understand the English speaker and responds in spoken English) or writing notes back and forth. Accessible communication was constructed from these two measures, coded yes when the actual mode of communication was the same as the preferred (options: ASL, lip-reading, written notes) or ASL and no otherwise. Dissatisfaction with communication (vs. very or somewhat satisfied) was also used as a predictor in the equation of unmet need. Covariates captured predisposing, enabling, and need variables of the Behavioral Model (Gelberg et al., 2000; Aday & Andersen, 1974).

*Analytic Methods*
Using the survey data, unadjusted analyses portray sample characteristics; McNemar’s tests compare rates of preferred and actual methods of communication. Logistic regression models explore associations of accessible communication, dissatisfaction, and unmet need for care.

A grounded-theory principle was followed to code the qualitative data (Gall et al., 2007; DeNardo & Levers, 2002). The analysis process included sifting through the data, filtering out significant information, identifying patterns, and constructing a framework for imparting what was revealed. Text units, sequences of words (e.g. video remote interpreting, on-site interpreters, writing back and forth, scheduling/rescheduling appointments, lip-reading, interpreter not-show up, hospital contracts, and communication access in the lobby) in each interviewees’ responses were coded and then compiled (DeNardo & Levers, 2002; Gall et al. 2007). The code-represented data were then assigned to inductive categorical themes that emerged during coding. These themes were represented by strong indicators and illustrative text units. Findings are portrayed as the top three of eight categorical themes using strong indicators.

The trustworthiness of the qualitative data was assured by means of a several strategies throughout the research process (Gall et al., 2007). The conversation style during the interview sessions was honest, truthful, and straightforward. Interview questions and answers were authentically documented via video and timely transliteration in order to achieve verisimilitude. The volunteers’ responses to the interview questions included direct quotes and descriptions of specific and concrete information for the qualitative research. Peer examination (member checking) was conducted with 12 study participants and 1 nonparticipant through a process of
review and commenting on a preliminary draft of the findings to enhance meaning and
dependability of the findings.

Results

Quantitative Findings

The sample showed variation by some measures of socio-demographics (Table 1). For example,
45% of the study population had a high school education or less, while 32% held a graduate
degree. Nearly 19% were covered by Medicaid and 51% by Blue Cross Blue Shield. Eighty-one
percent identified as Deaf; almost 5% identified as Deaf-blind. While 81% reported accessible
communication, nearly 11% were dissatisfied with their communication with their healthcare
provider, and 16% reported unmet need for care. While 65% preferred to use a professional sign
language interpreter to communicate with their providers, only 45% of respondents did so (not
shown). Instead, people were more likely to have relied on lip-reading plus speaking (18%),
written notes (22%) and direct sign or cued language (10%).

Logistic regression of dissatisfaction with communication (Table 2) indicated that reporting
accessible communication was associated with 81% lower odds of dissatisfaction with
communication. Living alone was associated with five times the odds of dissatisfaction with
communication. Furthermore, logistic regression of unmet need for care indicated that
dissatisfaction with communication was associated with nearly nine times the odds of reporting
having unmet need for care. Being male and having higher than a high school education each
was associated with 96% lower odds of reporting unmet need. Notably, having a personal doctor as the usual source of care was associated with 96% lower odds of reporting unmet need for care.

**Qualitative Findings**

Among interview participants, 85% were Deaf or Deaf-blind; the remainder were hard of hearing. They had similar characteristics to survey participants except that more, 19%, were Black. The most common themes of communication issues were VRI, on-site interpreters, and writing back and forth when communicating with healthcare providers. Data analytics and examples of participants’ responses to structured questions are shown in Table 3. Participant responses to the interview question had strong indicators in their storytelling experiences about communication with doctors, nurses, and other professionals in the healthcare settings. The percentage of strong indicators from retrieved text units differed from theme to theme.

Frustration with VRI was a common theme throughout.

*Sometimes VRI causes technical problems such as breakdowns or frozen screen, which is frustrating*

Participants described VRI interpreters who were difficult to follow or understand. They also described how a doctor and nurse would talk with one another while the VRI screen was turned away from them, making it impossible for the Deaf individual to participate in the conversation.

VRI technical difficulties identified included connectivity issues, especially with staff unprepared to deal with wifi, and/or staff not knowing how to set up the VRI equipment. Consequently, problems included freezing or blurring on the VRI screen, having to resort to
writing back and forth, lip-reading, and rescheduling appointments. Frequently, VRI was described as a waste of time.

Participants described on-site interpreters who were not qualified to provide medical interpreting services, misunderstandings resulting from writing back and forth, and delays from rescheduling appointments. They emphasized the importance of using on-site interpreters qualified in medical interpreting and planning for accommodation in order to ensure accessible communication.

*I still prefer professional sign language interpreters who are certified to interpret ASL.*

Participants explained that an on-site interpreter is able to convey more feeling and understanding of what is communicated and to show more action with facial and body expression thereby supporting more effective and efficient communication.

Participants described writing notes back and forth as difficult to understand and common as an easy substitute for interpreter services.

*I need live interpreters, not writing back and forth because I don’t understand English. They gave me notes. [sighs]*

Participants had to be insistent to obtain the qualified interpreting services appropriate for their needs.

*I said no, and we want a live, in-person interpreter. They respected me, but I had to wait 1-2 hours. They did not call for interpreters until I arrived.*

Participants described how qualified medical interpreting services were frequently unavailable.

*I had to stand up and ask staff at the front desk to reschedule an appointment because that interpreter was not certified.*
Discussion

This study describes evidence of Deaf participants’ frustrations with the disparities in communication access that they experienced with healthcare providers in North Carolina. Existing literature shows that communication access has long been challenging for Deaf individuals working with healthcare providers (Hommes et al., 2018; Kushalnagar et al., 2018; Kuenburg et al., 2016; McKee, Schlehofer et al., 2011; Mudrick & Schwartz, 2010; Steinberg et al., 2006; Iezonni et al., 2004). Findings from this mixed methods study revealed that participants had concerns and were upset and even angry about the lack of effective and efficient accessible communication with their healthcare providers. Patient expression of distress over poor communication access has been a common theme over time (Kushalnagar et al., 2019; Sheppard, 2014; McKee, Schlehofer et al., 2011).

The most common barriers to accessible communication throughout North Carolina identified here were VRI technical problems, quality of sign language interpreting services, and difficulties of writing back and forth, all of which caused communication breakdowns. Communication via VRI was considered not user-friendly, creating frustrations for both Deaf individuals and their professional healthcare providers. These findings provide nuanced information on reasons for dissatisfaction with VRI that help to explain existing evidence on dissatisfaction (Kushalnagar et al., 2019). Even though providers attempted to adapt to VRI issues by lip-reading/speech or writing notes back and forth, both methods undermine the ability to communicate complex medical information for decision-making and informed consent due to limited English proficiency and because they create time constraints that lead to abbreviated communications.
even among those who are bilingual (McKee, Paasche-Orlow et al., 2015; McKee, Schlehofer et al., 2011; Singleton et al., 2004; GAO, 1988).

While ASL users prefer to use a professional sign language interpreter on-site to communicate with clinicians, most actually use some other form of communication (i.e. VRI, lip-reading or writing notes). Findings supported the study hypotheses that accessible communication would act as an enabling characteristic in the Behavioral Model, associated with lower odds of dissatisfaction with communication. Dissatisfaction with communication was associated, in turn, with greater odds of unmet need for care. These findings are consistent with earlier work, indicated high rates in the Deaf community of ineffective communication and resulting miscommunications between patient and provider, frustration over accessibility of communication and poor healthcare use (Hommes et al., 2018; McKee, Winters et al., 2015; Sheppard, 2014; McKee, Schlehofer et al., 2011; Steinberg et al., 2006; Iezzoni et al., 2004). This is consistent also with prior evidence that language concordance among ASL users and their healthcare providers is associated with increased receipt of preventive services and cancer screening communications (Kushnagar et al., 2018; McKee, Barnett et al., 2011). More broadly, findings are consistent with evidence from a systematic review of the Behavioral Model where language and ability to communicate in English were found to be common measures of enabling characteristics (Babitsch et al., 2012). Patient-engaged care, such as interaction with the provider and shared decision-making, measures within the English-speaking population that might be similar to our measure of satisfaction with communication, have also been shown to be associated with unmet need for care among adults (Hong et al., 2019).
Additionally, individuals who lived alone had greater odds of dissatisfaction with communication which may reflect the absence of a partner who could provide emotional support and/or brain-storm strategies to effectively address barriers to accessible communication. This finding is similar to the body of evidence that being married is commonly associated with better access to care (Babitsch et al., 2012). Also, people who did not have a personal doctor as their usual source of care were more likely to report unmet needs consistent with the Behavioral Model. It may be that having a personal, on-going relationship with one’s clinician provides the opportunity to identify communication strategies that work both for the individual and for the practice. For example, Deaf individuals have described the importance of communicating directly about health topics to achieve a mutual bond and understanding (Havercamp et al., 2020).

**Limitations**

The survey findings reported here are based on a small convenience sample of individuals who have direct and indirect connections with state services for the Deaf and Hard of Hearing. Many respondents were middle-aged females with college degrees who may have greater efficacy in obtaining communication supports that the typical Deaf individual. Understanding of Deaf individuals’ receipt of accessible communication accommodations and the resulting patient-reported and health outcomes will benefit greatly from the development of a nationally representative sample of Deaf individuals. Survey techniques using current panels of participants, such as with the Health Reform Monitoring Survey, are promising strategies to develop current, affordable data sources for rare populations that are representative of national populations (Thomas et al., 2018; Hall et al., 2017; Long et al., 2014). The small sample used
here may hide important disparities in unmet needs by race and age group. In contrast, the interview sample described here reflected more diversity in characteristics and opinion. The development and implementation of web surveys in ASL is still novel (Kushalnagar et al., 2017; McKee et al., 2013). These efforts will benefit from application of the knowledge base in web-based English-language surveys to avoid sampling and response biases through protocol and question design (Dillman et al., 2014). Critically, only once high-quality representative data are available to describe disparities in accessible communication and outcomes, can the field advance to discover who succeeds in obtaining accessible communication accommodations, how, in what manner, and how to facilitate these successes for other Deaf individuals who use ASL.

Implications for Public Health Policy and Practice

Access to effective and efficient communication for Deaf individuals is vital to address disparities through the receipt of appropriate healthcare services that yield positive health outcomes. State governments should partner with stakeholder advocates and academics to develop and implement comprehensive public health policy and practices that can eliminate communication barriers among Deaf and Hard of hearing individuals in all aspects of healthcare (McKee et al., 2013). Stakeholders have long emphasized that, in the practice setting, health care providers should consult with the Deaf patient regarding their preferred communication aids and services and accommodate accordingly (McKee, Moreland et al, 2015; Iezzoni et al., 2004). Critically, research building improved policy should be undertaken in partnership with Deaf researchers and community stakeholders (Singleton et al., 2014).
Newer work emphasizes the importance of being bilingual in signed and spoken/written language to support language development in Deaf children and their health literacy and health outcomes as adults (Wilkinson & Morford, 2020; Moreland et al., 2015). Bilingual presentation of educational material online has been associated with increased knowledge gain for ASL users (Palmer et al., 2017). Among Deaf individuals fluent in written English, electronic communication has the potential to improve patent-provider communication (Ryan & Kushnalar, 2018). Conversely, it is critical that messaging about public health issues such as the coronavirus disease 2019 (COVID-19) pandemic reflect recommended low reading levels that are also accessible for Deaf individuals (Neuhauser et al., 2013; McKee & Paasche-Orlow, 2012).

Increased reliance on video conferencing and patient portal communication motivated by the COVID-19 pandemic may help to reduce health communication disparities (Wosik et al., 2020; Ryan & Kushnalagar, 2018). As telemedicine video conferencing becomes routine, practices may be motivated to invest in high quality technology systems. Further, telemedicine video conferencing works well for Deaf individuals because each participant, patient, provider and interpreter, can be seen and heard equally. On the other hand, barriers due to patient computer and wifi resources and medical interpreting qualifications of interpreters remain. Future research should examine the changes in accommodation methods over the pandemic, their impacts and disparities.

Workforce development initiatives to expand the native ASL user healthcare workforce also have potential (Havercamp et al., 2020; Hall et al., 2019; McKee, Barnett et al., 2011; Steinberg
et al., 2006). A growing University of Rochester School of Medicine and Dentistry program provides dedicated interpreters to medical faculty and trainees (Hall et al., 2019). By supporting dedicated interpreters and technical staff, interpreters become collaborative partners informed about the Deaf professional’s work and technical language. Interpreters interpret both formal and informal communications and save significant time that is otherwise required to arrange communication accommodation. ASL language concordance between Deaf patients and providers has been associated with greater use of preventive services and greater satisfaction with communication (McKee, Barnett et al., 2011; Steinberg et al., 2006). Language concordance has also been important in community-based interventions. A community educational group intervention lead by lay facilitators who were ASL users generated high satisfaction among participants (Havercamp et al., 2020).

The Americans with Disabilities Act (ADA, 1991) and the Rehabilitation Act of 1973 (USDHEW, 1978) apply to all healthcare providers of both physical and mental health care, hospitals, nursing homes, psychiatric and psychological services, offices of private physicians, dentists, health maintenance organizations, and health clinics, regardless of the size of the office or the number of employees. Under this law, effective communication between Deaf patients, caregivers and healthcare providers must be supported by qualified professional sign language interpreters (i.e. those specializing in medical interpreting). Qualified sign language interpreters are certified by state government licensing boards or the National Registry of Interpreters for the Deaf. Certified interpreters must satisfy national professional standards of competency in the language, interpretation, and practice of ethics and professionalism (Olson & Swabey, 2017; Nanoka, 2016; Registry of Interpreters, 2007).
The findings reported here emphasize the fact that professional interpreting service delivery in healthcare settings is challenging and complex. It can be difficult to locate a qualified interpreter on short notice, especially for emergencies. When qualified on-site interpreters are not available for appointments or when there is an urgent need for communication access in the emergency department, VRI may be ideal to serve as a stop-gap measure, but only until a qualified on-site interpreter can found. The use of two VRI units and equipment with high-speed connectivity can mitigate some of the problems identified here. Having an extra unit provides flexibility for on- and off-site users and helps ensure there is a back-up if the first unit breaks, or if more than one Deaf or Hard of hearing individual comes to the location needing emergency care at the same time. Nonetheless, VRI will always be limited for a number of reasons: 1) VRI is inaccessible to Deaf patients in certain physical positions, such as patients who are in a prone position; 2) VRI may be inappropriate in situations where regional sign language dialects require the use of an on-site local interpreter who is equipped to interpret local dialects and 3) VRI is inaccessible for Deaf patients with vision impairments (NAD, 2018). State government officials and health policymakers will benefit from engagement with Deaf and hard of hearing people in different geographical communities when developing and adopting public policy and regulations to address disparities in access to effective healthcare. Quality engagement by Deaf and Hard of hearing patients in research and implementation is necessary to develop the best solutions that ensure mutual satisfaction and better support health equity in diverse Deaf and Hard of hearing communities (Iezzoni et al., 2004).
Conclusion

The findings of this paper indicate that many Deaf ASL users continue to experience disparities in access to accessible communication in healthcare, a situation that continues to undermine their understanding of optimal health options for themselves, their families, and their communities (Hommes et al., 2018). As a result, Deaf individuals who are dissatisfied with their health communication experience greater unmet need for care. The full effects of these communication disparities result in adverse health outcomes (McKee, Schlehofer et al., 2011). Findings document current problems, which provide the rationale for and new opportunities to improve accessible communication by working more effectively with Deaf patients through qualified professional ASL interpreters.

Acknowledgements

This research was funded by North Carolina Department of Health and Human Services, Division of Services for the Deaf and Hard of Hearing.

The authors wish to acknowledge the contributions of Glen Silver, Human Service Planner and Evaluator of NCDSDHH.
References


[https://doi.org/10.1177/1049732318779050](https://doi.org/10.1177/1049732318779050)


[https://doi.org/10.2105/ajph.2011.300247](https://doi.org/10.2105/ajph.2011.300247)


Hall, W. C., Elliott, M., & Cullen, J. P. (2019). Designated interpreters: A model to promote the diversity and inclusion of deaf professionals in academic medicine. *Academic Medicine, 94*(5), 697-700. [https://doi.org/10.1097/acm.0000000000002570](https://doi.org/10.1097/acm.0000000000002570)


Kushalnagar, P., Paludneviciene, R., & Kushalnagar, R. (2019). Video remote interpreting technology in health care: Cross-sectional study of deaf patients’ experiences. *JMIR Rehabilitation and Assistive Technologies, 6*(1), e13233. [https://doi.org/10.2196/13233](https://doi.org/10.2196/13233)


https://doi.org/10.1377/hlthaff.2013.0934


https://doi.org/10.1080/10810730.2012.712627


https://doi.org/10.1080/10810730.2015.1066468


https://doi.org/10.1016/j.dhjo.2011.04.001


https://doi.org/10.2105/ajph.2013.301343


https://doi.org/10.1891/1521-0987.17.3.114

https://doi.org/10.1097/jhq.0000000000000038

https://doi.org/10.1016/j.dhjo.2016.07.002


https://doi.org/10.1080/10810730.2018.1527875

https://doi.org/10.1016/j.dhjo.2020.100932

https://doi.org/10.1002/2327-6924.12087


<table>
<thead>
<tr>
<th>Characteristics</th>
<th>N</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age group</td>
<td>189</td>
<td></td>
</tr>
<tr>
<td>18 to 34</td>
<td></td>
<td>24 (12.7)</td>
</tr>
<tr>
<td>35 to 64</td>
<td></td>
<td>129 (68.2)</td>
</tr>
<tr>
<td>65 or older</td>
<td></td>
<td>36 (19.1)</td>
</tr>
<tr>
<td>Sex</td>
<td>189</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td></td>
<td>46 (24.3)</td>
</tr>
<tr>
<td>Female</td>
<td></td>
<td>143 (75.7)</td>
</tr>
<tr>
<td>Race</td>
<td>189</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td></td>
<td>161 (85.2)</td>
</tr>
<tr>
<td>Black</td>
<td></td>
<td>16 (8.5)</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td>10 (5.3)</td>
</tr>
<tr>
<td>Education</td>
<td>189</td>
<td></td>
</tr>
<tr>
<td>High school or less</td>
<td></td>
<td>84 (45.0)</td>
</tr>
<tr>
<td>College</td>
<td></td>
<td>43 (22.5)</td>
</tr>
<tr>
<td>Graduate degree</td>
<td></td>
<td>62 (32.5)</td>
</tr>
<tr>
<td>Insurance type</td>
<td>166</td>
<td></td>
</tr>
<tr>
<td>Medicaid</td>
<td></td>
<td>31 (18.7)</td>
</tr>
<tr>
<td>Medicare</td>
<td></td>
<td>73 (44)</td>
</tr>
<tr>
<td>Blue Cross Blue Shield</td>
<td></td>
<td>84 (50.6)</td>
</tr>
<tr>
<td>Hearing status</td>
<td>189</td>
<td></td>
</tr>
<tr>
<td>Deaf</td>
<td></td>
<td>153 (81.0)</td>
</tr>
<tr>
<td>Deaf-Blind</td>
<td></td>
<td>9 (4.8)</td>
</tr>
<tr>
<td>Hard-of-Hearing</td>
<td></td>
<td>27 (14.3)</td>
</tr>
<tr>
<td>Lives alone</td>
<td>189</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>33 (17.5)</td>
</tr>
<tr>
<td>Usual source of care: personal doctor</td>
<td>177</td>
<td>158 (89.3)</td>
</tr>
<tr>
<td>Need for health care in the past 12 months</td>
<td>188</td>
<td></td>
</tr>
<tr>
<td>No need</td>
<td></td>
<td>58 (30.9)</td>
</tr>
<tr>
<td>Medical or dental care</td>
<td></td>
<td>102 (54.3)</td>
</tr>
<tr>
<td>Behavioral health care</td>
<td></td>
<td>25 (13.3)</td>
</tr>
<tr>
<td>Vision or hearing aids</td>
<td></td>
<td>57 (30.3)</td>
</tr>
<tr>
<td>Rural residence</td>
<td>187</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>39 (20.9)</td>
</tr>
<tr>
<td>Accessible communication</td>
<td>167</td>
<td>135 (80.8)</td>
</tr>
<tr>
<td>Dissatisfied with communication</td>
<td>166</td>
<td>18 (10.8)</td>
</tr>
<tr>
<td>Not fully satisfied with communication</td>
<td>166</td>
<td>79 (47.6)</td>
</tr>
<tr>
<td>Unmet need for healthcare</td>
<td>177</td>
<td>29 (16.4)</td>
</tr>
</tbody>
</table>

Note. n=189
Table 2. Logistic regression of dissatisfaction with communication and unmet need for care among ASL users

<table>
<thead>
<tr>
<th></th>
<th>Dissatisfaction with Communication (C-statistic=0.805)</th>
<th>Unmet Need for Care (C-statistic = 0.911)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Odds Ratio</td>
<td>95% CI</td>
</tr>
<tr>
<td>Accessible communication</td>
<td>0.19</td>
<td>0.05 - 0.69</td>
</tr>
<tr>
<td>Dissatisfaction with communication</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>35 to 64</td>
<td>2.07</td>
<td>0.31 - 13.89</td>
</tr>
<tr>
<td>65+</td>
<td>0.37</td>
<td>0.02 - 7.18</td>
</tr>
<tr>
<td>Male</td>
<td>1.10</td>
<td>0.29 - 4.16</td>
</tr>
<tr>
<td>Minority</td>
<td>0.64</td>
<td>0.12 - 3.41</td>
</tr>
<tr>
<td>More than high school education</td>
<td>1.00</td>
<td>0.15 - 6.73</td>
</tr>
<tr>
<td>Insurance type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicaid</td>
<td>2.26</td>
<td>0.50 - 10.31</td>
</tr>
<tr>
<td>Medicare</td>
<td>1.49</td>
<td>0.35 - 6.30</td>
</tr>
<tr>
<td>Blue Cross Blue Shield</td>
<td>0.68</td>
<td>0.14 - 3.35</td>
</tr>
<tr>
<td>Lives alone</td>
<td>5.10</td>
<td>1.34 - 19.37</td>
</tr>
<tr>
<td>Usual source of care: personal doctor</td>
<td>0.37</td>
<td>0.07 - 1.92</td>
</tr>
<tr>
<td>Need for health care in the past 12 months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical or dental care</td>
<td>2.52</td>
<td>0.57 - 11.21</td>
</tr>
<tr>
<td>Behavioral health care</td>
<td>0.63</td>
<td>0.09 - 4.29</td>
</tr>
<tr>
<td>Vision or hearing aids</td>
<td>0.32</td>
<td>0.07 - 1.42</td>
</tr>
<tr>
<td>Rural residence</td>
<td>0.45</td>
<td>0.08 - 2.49</td>
</tr>
</tbody>
</table>

N=166
### Table 3. Strong Indicators of Patterns for Responses

<table>
<thead>
<tr>
<th>Inductive Categorical Themes</th>
<th>Total Text Units</th>
<th>Retrieved from Total Text Units</th>
<th>Strong Indicators of Patterns from Retrieved Text Units</th>
<th>Percentage of Participant Responses</th>
<th>Transliterated Quotes</th>
</tr>
</thead>
</table>
| Video Remote Interpreting (VRI)      | 53 of 54        | 365                             | 33                                                     | 98%                                 | R5: “I hate VRI because it causes frozen screens and blurring.”  
R43: “No, I am not satisfied with VRI because of the terrible internet connection.” |
| On-site interpreters                 | 49 of 54        | 205                             | 37                                                     | 91%                                 | R12: “They realized that it is best to remain with live [on-site] interpreters because VRI would cause problems. They agreed to call for a live interpreter for my son’s next appointment.”  
R41: “I need live interpreters, not writing back and forth because I don’t understand English. They gave me notes. [sighs] I told them I preferred live interpreters for easy communication. I understand ASL much better through live interpreters.”  
R45: “Sometimes they are not qualified to interpret in medical settings. One time I could not understand the interpreter because she was not qualified. I had to tell them that they had to replace the interpreter.” |
| Writing back and forth               | 29 of 54        | 56                              | 9                                                      | 54%                                 | R27: “Writing back and forth sometimes caused a mental block. It is hard for me to express my feelings or thoughts when writing back and forth. It is much easier to express my feelings and thoughts in my own ASL through live interpreters.”  
R40: “VRI did not work well for me. I prefer live interpreters. Doctors are stubborn and won’t get live interpreters for me. My doctor wrote notes that required me to write back and forth.”  
R37: “When we had to wait for VRI to be brought in, we had to write back and forth. I had no choice but to be stuck with the writing back and forth.” |
Figure 1. Behavioral Model of Healthcare Use

Aday & Andersen, 1974
Figure 2. Screenshot of a question in the online survey presented in both ASL and English.
Figure 1. Behavioral Model of Healthcare Use

Figure 2. Screenshot of a question in the online survey presented in both ASL and English