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Sylvia M. Blomstrand, C. L. Stark, C. A. McCarty, and A. Greminger

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Exploring d/Deaf community perspectives regarding inclusive/accessible healthcare

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Abstract

Background: d/Deaf [1]patients face substantial barriers obtaining healthcare, including communication challenges, cultural differences, and unique psychosocial needs. Healthcare providers are generally undereducated on how to best care for this patient population. This project aims to identify healthcare disparities and areas for improvement in healthcare provider education from the d/Deaf-patient perspective.

Methods: A 40-question survey was distributed to d/Deaf groups across the United States. Nine focused interviews were conducted with d/Deaf patients.

Results: 62 d/Deaf individuals responded to the survey. Due to communication difficulties with healthcare providers, 33% did not access healthcare when needed, 52% had medical questions go unanswered, and nearly 40% did not understand their health. Focused interviews found that d/Deaf patients continue to face healthcare barriers due to communication difficulties, poor awareness of d/Deaf needs, and accessibility concerns. Survey and focused interview participants agreed improved healthcare provider education and awareness would improve their care. **Discussion:** Data suggest that multifactorial healthcare disparities continue to affect the d/Deaf population and d/Deaf patients believe improved education of healthcare providers is paramount to improve healthcare. Specific curricular areas to improve upon include: communication, cultural/psychosocial issues, and improved awareness of the d/Deaf community.

Conclusions: The d/Deaf community faces substantial barriers to accessible healthcare that can be improved by improved healthcare provider curriculum and awareness.

Keywords: Deaf, healthcare disparities, curriculum, health literacy, physician training.

Introduction

In 2018 in the United States, nearly twelve million individuals were living with deafness or profound hearing loss (Lauer et al., 2020). Research has consistently shown poorer health outcomes for these individuals, including: higher rates of childhood abuse, mental health disorders, and chronic disease; and lower rates of prenatal care and cancer screening (Horner-Johnson et al., 2019; Kushalnagar et al., 2019; Kvam, 2004; Lindén-Boström & Persson, 2015). The causes of these health disparities are multifaceted.

Beginning in childhood and through adulthood, d/Deaf individuals experience higher rates of poverty and have less access to medical care (Boss et al., 2011; Garberoglio et al., 2019). Furthermore, d/Deaf populations host a low health literacy rate due to substantial communication difficulties in healthcare settings and low familiarity with health specific language (McKee et al., 2015). Other exacerbating factors contributing to health disparities include limited data on the health of d/Deaf persons, challenges in accessing ASL interpretation, and other coincident medical conditions (Barnett, 2002)

Sylvia M. Blomstrand, University of Minnesota Medical School, Duluth campus

C. L. Stark,

C. A. McCarty, University of Minnesota Medical School, Duluth campus

A. Greminger, University of Minnesota Medical School, Duluth campus

Corresponding author: Amy Greminger, MD Assistant Professor Department of Family Medicine and Biobehavioral Health, Duluth University of Minnesota Medical School Duluth 145 Med 1035 University Drive Duluth MN 55812-3031 Phone: 612-839-4356 Email: agreming@d.umn.edu

Cumulatively, this results in high rates of mistrust and frustration with the healthcare system among the d/Deaf community (Steinberg et al., 2006).

One overshadowing reason for poor health outcomes and healthcare access is failure of healthcare providers to communicate and effectively care for d/Deaf patients (Chaveiro et al., 2009; Hommes et al., 2018; McKee et al., 2015; Naseribooriabadi et al., 2017). Healthcare providers have a responsibility to effectively communicate with and provide care to d/Deaf individuals but receive little training in medical school on aspects of caring for this underserved, minority patient population (Chaveiro et al., 2009; Liaison Committee on Medical Education, 2020). The Liaison Committee on Medical Education (LCME) requirements for medical school curriculums include diverse cultural competence and communication skills practice (Liaison Committee on Medical Education, 2020). Studies have found that inclusion of d/Deaf social determinants of health and cultural education leads to drastic improvements in medical student and physician attitudes about and skills with d/Deaf patients (Barnett, 2002; Hoang et al., 2011; Thew et al., 2012).

With all of this in mind, this project had two aims: to identify current d/Deaf healthcare disparities related to healthcare providers and to find areas for improvement in healthcare provider education and awareness from the deaf-patient perspective.

Methods

Survey Methods:

An electronic, 40 question survey in written English was created by study staff and face validity was confirmed by input from d/Deaf individuals (Two ASL professors, and three non-medical d/Deaf community members were involved in the review process.) The pretesting process enlisted d/Deaf people who helped to determine readability, timing, and accessibility. The survey was reviewed and approved by University of Minnesota IRB. Demographic questions incorporated in this survey were selected from the PhenX Toolkit version [April 30, 2021, Ver 38.0](#) (Hamilton et al., 2011). The survey was distributed to d/Deaf and hard of hearing groups in the United States through different university-affiliated groups, Facebook and other social media based groups, as well as with the help of several state agencies, and email chains. The survey was filled out anonymously but was designed for

individuals who self identified as d/Deaf or profoundly hard of hearing and were > 18 years old. It was available for a duration of six weeks, and took approximately 20 minutes to complete. The survey was divided into four areas of interest: demographic characteristics, healthcare use, healthcare accessibility, and experiences with healthcare providers. There was an open-ended question at the end for participants to enter thoughts and opinions on healthcare improvement.

SAS v.9.4 (SAS Institute Inc., Cary NC) was used for analysis. Descriptive analysis was conducted for each survey item on the entire sample, means and standard deviations for continuous variables and frequencies and proportions for categorical variables. The agreement scores (7-point Likert scale items) were treated as continuous variables in the analysis. Sub-group analysis was conducted for four groups: Born deaf vs all others, household income (\leq \$49,999 vs \geq \$50,000), education (High school or less, Some college/Associate's degree/Bachelor' degree, and Master's degree or more), and age (18 to 30, 31 to 60, 61 or older). Average agreement scores (mean and standard deviation) were reported by subgroup for each of the 16 agreement items. Four of the agreement items were selected *a priori* for comparative testing, t-tests for the subgroups with two categories and ANOVAs for those with three categories.

Interview Methods:

Through the survey, participants were able to self identify as being willing to participate in the qualitative portion of this study: focused interviews. We used the survey results to inform our questions. Beyond individuals who expressed an interest via the survey, additional participants in the focused interviews were identified via referral from survey participants (snowball sampling). The focused interview process was reviewed and approved by the University of Minnesota IRB, took place over Zoom video call, and lasted approximately 1 hour. All participants expressly gave consent before starting interviews. Consent was obtained by asking patients to type in their consent over zoom. The consent process was explained both in writing (in the chat box via zoom) and verbally with interpretation. Interviewees had opportunities to ask questions during the process, and all questions were answered.

There was one d/Deaf and blind participant. This participant preferred to communicate verbally, and had an interpreter connected separately per her preference. Additionally, one participant elected to answer the questions in written form. The interviewers, S.B and C.C.L., were a fourth-year medical student and an ASL student, respectively. They were trained by a trained qualitative researcher in focus group facilitation. No participants had a prior relationship with any interviewers. Each interview had one or two participants for a total of nine focused interviews, one participant was unable to participate due to technology problems. Interviews were recorded using Zoom. One interviewer facilitated discussion and one interviewer took notes. Closed captioning and ASL interpreter services were both provided for all interviews. Following a brief introduction where interviewers shared their background and interest in d/Deaf healthcare, participants were asked the same six pre-selected, pre-tested questions and follow up questions based on their answers (Table 1). Transcripts were not sent to participants, although if they had further thoughts or changes they were encouraged to reach out to interviewers. Participants received a \$100.00 honorarium upon completion. Analysis of focus groups followed the theoretical framework of grounded theory and content analysis. Transcripts of focused interviews were reviewed by two researchers and themes were identified independently. All major statements were assigned a theme and any discrepancies were discussed and agreed upon. Themes included were mentioned by at least four participants. Interview questions are shown in Table 2.

Table 2. Preselected focused interview questions.

1. What are some examples of healthcare working well for you?
2. What are some examples of healthcare not working well for you?
3. If your healthcare provider could learn a few things about the d/Deaf community, what would be most important for them to know?
4. Do you feel like your deafness has impacted your overall health and if so, in what ways?

5. What do you see as the most important healthcare issue facing the d/Deaf community?

6. What is the most important thing about healthcare, that if changed, would improve it for you?

*Six pre-tested, pre-selected questions asked at every focused interview. Follow-up questions were asked based on participant responses.

Survey results

Demographics

Of the 62 respondents to the survey, 86% were female. Age ranged from 18 to 91 years, distribution is shown in Figure 1. The income distribution of respondents is shown in Figure 2. Respondents were primarily white (90%) with 5% reporting Black of African American race/ancestry, 1.7% reporting Chinese, 1.7% Filipino, and 5% "other". 85% of respondents reported "not Hispanic, Latino, or of Spanish origin," (1.6% reported Mexican/Mexican American/Chicano, and 12.9% did not respond). 58% of respondents reported having attained at least a bachelor's degree.

Among all participants, 32% reported using cochlear implants and 80% reported using some other assistive hearing technology. Those with cochlear implants (n=19) were most likely to have been using them for over 5 years (90%). Similarly, those using other technology (n=48) were most likely to be using them for over 5 years (85%). The largest proportion of participants were born deaf (44%) and the smallest proportion report becoming deaf between 5-18 years old.

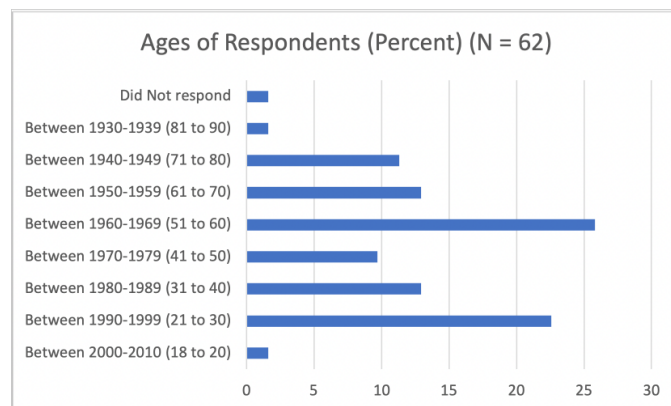


Figure 1

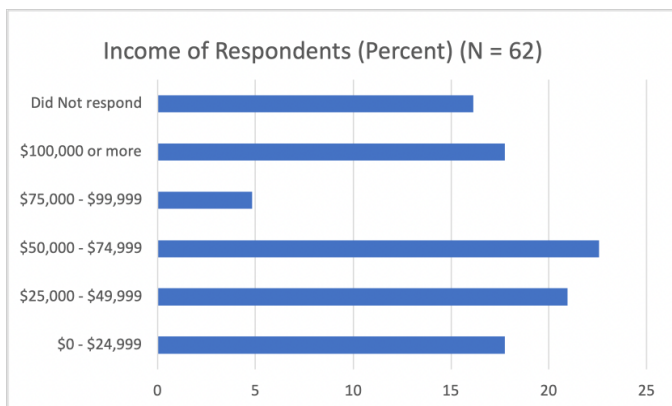


Figure 2

Healthcare use

Most participants reported that their most recent doctor visit was at a Clinic (64%). A wide variety of communication tools were used at the recent visit, except for Certified Deaf interpreter which was only reported by one participant. Messaging or emailing (68%) was a common method for communicating with doctors when not in person, followed by video phone or TTY (41%). Most participants report having a regular doctor[2] (93%), 49% had visited their doctor at least twice in the past year and 80% had visited at least twice in the past two years. In the past five years, 57% of participants had either no visits or one visit to an urgent care facility or ER and 85% had either no nights in the hospital or one.

Healthcare accessibility

In healthcare settings, patients identified the following communication methods as being used (Figure 3). Additionally, many participants identified communication challenges. Due to difficulties with communication with healthcare providers, 33% did not access healthcare when needed, 52% had medical questions go unanswered, nearly 40% did not understand their health, and 61% wished their physician could communicate better with them. More precise answers to these questions are shown in the figure below (Figure 4).

In the open-ended survey question, participants voiced the need for better accessibility in healthcare particularly with improved healthcare provider education and awareness on d/Deaf needs. A need for communication improvement with healthcare providers was desired by many respondents.

Common causes of these communication difficulties were reportedly: personal protective equipment use that interfered with lip reading, lack of healthcare provider’s understanding on how to use/find interpreters, not utilizing the d/Deaf patient’s preferred methods of communication, constant rescheduling of appointments due to lack of communicative resources, and low access to written or visual forms of communication (such as messaging, emailing, pamphlets).

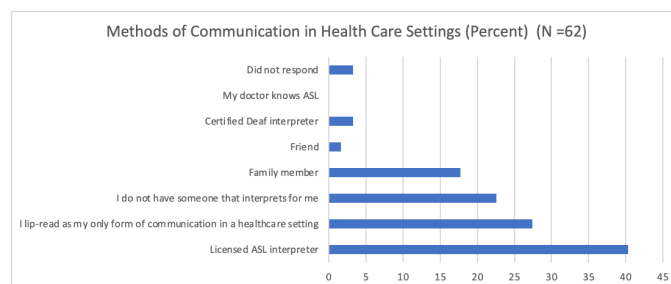


Figure 3

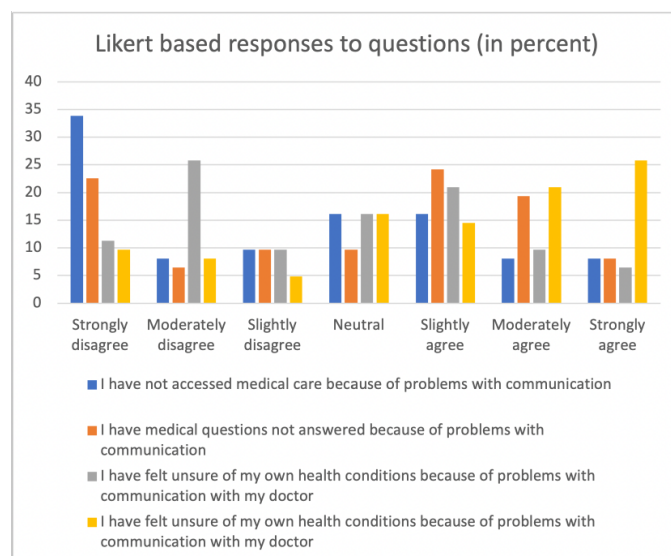


Figure 4

Experiences with healthcare providers

Survey participants were asked to rate their agreement on a 7-point scale from 1 (strongly disagree) to 7 (strongly agree), with 4 being neutral to these questions. Table 1 orders the questions from highest mean to lowest. Only one item was rated lower than 4.

Table 1: Experiences of d/Deaf patients with physicians (range 1-7, with 1=strongly disagree and 7=strongly agree)

Statement	Mean	Std Dev
I consider problems with communication when choosing a doctor	5.62	1.68
My doctors explain my health in a way that is easy to understand	5.49	1.37
My doctor understands how to communicate with me	5.39	1.55
I feel I can trust doctors	5.31	1.55
I feel respected by doctors	5.23	1.69
Overall I am happy with my experience with doctors	5.13	1.64
My doctor understands how to communicate with me when I am lip reading	4.98	1.80
I feel understood by doctors	4.85	1.55
I wish that my doctor could better communicate with me	4.84	1.98
My doctor understands how to communicate with me using an interpreter	4.79	1.55
My doctor understands how to communicate with me using technology	4.75	1.49
I have felt unsure of my own health conditions because of problems with communication with my doctor	3.65	1.80

Focused interview results

Focused interviews allowed deeper exploration of d/Deaf patient experiences and opinions on healthcare provider education. Seven participants were female, two were male. Three of the participants identified as people of color; two were indigenous peoples, one was an immigrant. There were many themes throughout the focused interviews, including

cultural sensitivity, communication barriers, and awareness of d/Deaf experiences and needs.

Cultural sensitivity

Seven of the nine participants mentioned respecting d/Deaf people and their culture as a large concern in healthcare. d/Deaf patients reported often feeling disrespected by healthcare provider cultural insensitivity. Participant five reported:

I know a deaf couple who had a baby last year. CPS, prompted by the hospital's concerns, was giving them a hard time about not getting hearing tests, even though deaf parents would be better at taking care of a deaf child than most hearing parents would be. This lack of respect can also lead to deaf people not trusting doctors as much and not getting the care they need.

Eight participants were concerned that healthcare providers view all d/Deaf patients as the same, making two incorrect assumptions. First, that all d/Deaf patients communicate the same way, which led to patients to communicate using unfamiliar methods. Second, that all d/Deaf patients are intellectually impaired or "lesser". In one case, a physician treated the interpreter as a caretaker - handing prescriptions or informational packets to the interpreter instead of the patient. Others reported being treated as though they could not understand the medical concepts with providers subsequently failing to explain medical concepts thoroughly. Respondents reported feeling frustrated by these generalizing assumptions and discussed the need to be treated as unique individuals with unique cultures and needs. Participant seven explained: educating them [healthcare providers] that we come from all walks of life... was essential to improving care.

Communication barriers

All nine participants mentioned difficulties with communication and accessibility of interpreters. Healthcare providers reportedly tended to assume what communication methods worked best, use complicated medical jargon, and restrict communication for d/Deaf patients. Furthermore, participants consistently reported healthcare providers incorrectly using interpreters, facing away while talking, wearing obstructive PPE, and not writing down complex concepts. Several participants

mentioned situations that made them feel ignored or dismissed by healthcare providers. Inpatient communication was challenging, one Deafblind participant reported their access to an interpreter limited to 4 hours a day. Finding in-person ASL interpreters in rural or emergency/urgent care settings was reported as difficult by six participants, often resorting to d/Deaf patients to writing or texting healthcare providers. Four participants reported video remote interpreting (VRI) as unreliable and frustrating due to technology issues and poor availability. One participant described a visit to an emergency room with chest pain, with no in-person ASL interpreter available, VRI not working, and poor written communication. She reported she felt terrified being unable to understand what was happening around her.

Eight participants reported extreme frustration because healthcare providers were unwilling to find or pay for interpreters and subsequently d/Deaf patients reported many rescheduled, cancelled, or forgone appointments. Participant five reported: A few years ago, I realized I was overdue for an appointment so I tried calling one place. I gave them interpreting agencies to call and then they got back to me. They were very inflexible, saying the interpreter wasn't available ... not telling me more available days or times for a better appointment. I was nervous that other offices would be like this too so I gave up on getting an appointment.

All participants were positive about healthcare providers that were willing to collaborate with d/Deaf patients on their preferred methods of communication and work to make their preferences possible. Online messaging and emailing with providers was consistently discussed as one of the most accessible interactions with healthcare providers. Having a primary care provider that knew them well and was sensitive to their communication needs was highly regarded.

Awareness

Seven participants mentioned lack of awareness of d/Deaf needs among healthcare providers. Four participants reported feeling unwelcome or "like a burden" whenever accessing medical care due to the accommodations needed and the subsequent impatience and hostility of healthcare providers. One respondent told a deeply concerning story of being

locked out of an emergency room - unable to get a very ill family member care - because this hospital required patients to use a phone to enter the emergency room. This lack of visibility and awareness led seven participants to report exhaustion and frustration in the healthcare setting because they have to constantly self-advocate and educate healthcare providers about deafness. Examples of this included: teaching healthcare providers how to care for them, how to communicate, and about their specific needs in healthcare. Participant seven described this as feeling "...like I am always hitting a wall..." with healthcare providers, participant six mentioned "it's not worth it... I don't want to experience that environment [healthcare]," participant eight stating "having to explain over and over again... it's so much time wasted trying to educate healthcare providers." Several other participants mentioned mental health, social and emotional wellbeing, and how this was compounded by low awareness of d/Deaf psychosocial experiences among healthcare providers. One participant described: The wear and tear emotionally on me, the hard work is definitely an impact on my health, my mental health particularly. - Participant One

Healthcare provider education

As far as the d/Deaf perspective on how healthcare providers could improve their healthcare, the following statements were given: Education would be the biggest thing that I could see impacting health care for the deaf by the health care providers.- Participant One

Continuously check in and make sure that you're hearing... do a teach back method... collaborate on the care plan... making sure that every step is really communicated well. - Participant Two

I would say treat us with respect and don't view us as a burden.- Participant Five

Become more aware of deaf people, understanding of deaf people, because not all deaf people are the same, just like any person... of course we all have our diversity, our differences. - Participant Seven

They [d/Deaf patients] might be a little bit slower to understand things, and they need more time put into

their care and they need to make sure that there's a good interpreter, maybe even a deaf interpreter. -

Participant Nine

Other responses included having medical staff educated on how to work with d/Deaf patients, not assuming what communicative tools are best for an individual, and being open and accepting to different cultures.

Discussion

Our study is limited in terms of it being a voluntary survey distributed via communities often associated with higher education communities. This leads to some differences in response from our sample as compared with the d/Deaf community in general. Additionally, survey respondents may be more likely to have had negative experiences with the healthcare community that they wanted to give voice to as a motivator for filling out the survey. Despite these limitations, we do feel that the survey and subsequent interviews provide an important window into the perceptions of the d/Deaf community. Given the commonalities of the interview responses, it makes sense that lack of cultural sensitivity, challenges with communication and lack of awareness of healthcare providers are common experiences that the d/Deaf community experience, and healthcare providers would benefit from more education on these issues. These issues were also noted in the survey results.

Given that our grant had a limited timeframe, we were not able to keep the survey open indefinitely, which could have limited our responses. However, the responses had already dropped off significantly as we had saturated requests for survey completion within our networks. Another potential limitation of the study was that we did not have a d/Deaf interviewer - in fact one respondent preferred to write her own answers. Again, we were limited by time and budget. This could potentially impact interpretation of the conversation. Individuals may also feel less psychologically safe when providing feedback about communication with people who are not members of the d/Deaf community. We mitigated these limitations as much as possible by explaining our interest in the topic and having a professional interpreter. Given that many of the barriers come from the interaction of the hearing and d/Deaf community, these limitations do mimic the barriers that the d/Deaf community

experiences routinely, but also can serve to unmask the barriers that are routine by putting a name to the experience, and helping people feel seen.

Future research could incorporate getting a more representative sample of d/Deaf individuals and looking to see how generalizable these results are. It may also be beneficial to look at the differing experiences of the Deaf community vs persons experiencing deafness. It might also be interesting to compare results of interviews conducted via an interpreter versus interviews which engage a Deaf interviewer.

Demographics

Connecting with a representative sample of marginalized groups can be challenging and is evident in survey demographics, which were skewed towards white, educated female responses. Interestingly, the average household income was comparative to the general deaf population (Garberoglio et al., 2019). The education level of survey respondents was much higher than the greater d/Deaf population, with 58% of respondents holding a Bachelor's degree compared to the reported 18% of the d/Deaf population (Garberoglio et al., 2017). Similarly, 86% of our survey sample was female despite males being a larger portion of d/Deaf population (Hoffman et al., 2017). While non-Hispanic white adults have the highest rates of profound hearing loss and deafness, the survey disproportionately represents this group and should be interpreted as such (Hoffman et al., 2017). Lastly, while it's difficult to know the exact rate of cochlear implant use, with 31% of our sample group with cochlear implants and under 200,000 implanted in the United States as of 2019, it's likely that the survey respondent pool has a disproportionately high rate of cochlear implants (U.S. Food and Drug Administration, 2019). These differences between our survey population and the deaf population as a whole may limit the generalizability of the data. Additionally, a lack of data from under-represented groups within the d/Deaf population may not reflect the totality of the d/Deaf experience. Though there may be limitations in the generalizability of the data, it does still have an important role in magnifying the viewpoints of the participants, and especially the content of our interviews.

Healthcare use

Many more respondents reported having a primary care physician (93%), as compared to the general population (Approx. 75%) (Levine et al., 2020). This may be reflective of the higher socioeconomic status of our survey respondents as compared to the general population, or may reflect that survey respondents are particularly engaged with the medical system.

Healthcare accessibility

Based on our findings, increased healthcare accessibility was a broad topic that encompassed improving communication, increasing awareness, and educating healthcare providers on d/Deaf patient needs.

Communication

At healthcare visits a variety of communication tools were reported as used, but were severely underutilized and family members commonly stood in as an interpreter – a striking accessibility issue. Lack of interpreter availability, VRI technology malfunctions, and refusal of insurance companies or healthcare providers to provide communication tools caused communication failures. This leads to the reported distrust, frustration, avoidance, and confusion among d/Deaf patients, contributing to poor health outcomes. Utilization of family members as interpreters is a controversial and ethically difficult situation for healthcare providers, as a better alternative may be difficult to find, especially in low-resource or emergency scenarios (Ho, 2008).

When communicating with d/Deaf patients, it is essential to understand each patient is an individual with unique communicative needs. There are varying levels of d/Deaf patient comfort and ability to read lips, communicate in ASL, and write in English. Assuming all d/Deaf patients are the same and therefore communicate the same, is detrimental to their healthcare, and by asking patients what methods they prefer – and working to make that method available – eliminates many communicative problems. Interestingly, survey respondents noted commonly using lipreading in health care settings. Lipreading has been found to only have 20% accuracy, which is inadequate for use in a healthcare setting (Altieri et al., 2011). Healthcare providers have a legal and ethical responsibility to communicate in

the patient's preferred method, but since lipreading is a poor form of communication, it may not be in providers or patients' best interests to utilize it as the sole form of communication. Communicating effectively and providing the means with which to communicate is required by law and healthcare providers should have alternative communication method options readily available for d/Deaf patients (Hoffman, 2011) Of course, each individual d/Deaf patient has unique needs, with whom providers should collaborate to find which method works best and utilize teach-back methods to ensure understanding.

Awareness/education of the healthcare community

Increasing awareness of d/Deaf patients in the healthcare setting improves healthcare accessibility. Participants expressed feeling exhaustion and frustration at having to constantly advocate for themselves and educate healthcare providers on d/Deaf culture, psychosocial and accessibility needs. Additionally, when it comes to d/Deaf culture and healthcare, it is important for healthcare providers to be aware the d/Deaf community is diverse. Many participants saw improved healthcare provider education as a solution to the numerous barriers d/Deaf patients faced. The consensus across survey and focus group participants was that increased visibility of the d/Deaf community and their needs in healthcare was imperative, and that psychosocial challenges and d/Deaf culture should be taught to healthcare providers.

Experiences with healthcare providers

Participants' responses varied greatly when asked about subjective experiences with healthcare providers. The overall positive Likert scores around experience with doctors from many patients may reflect a selection bias; though there appear to be many providers who lack awareness around the d/Deaf community, it appears that patients are often able to ultimately connect with one or more providers who are more culturally competent when choosing their primary care doctor. In the interviews, we got a more in depth look at the range of experiences that patients have. Each individual had at least one story of an interaction with a healthcare professional that went well, often with primary care providers willing to collaborate, ask questions, take extra time, and get to

know each patient as an individual. Each individual also had at least one negative interaction, usually due to poor communication, inflexibility, ignorance, or disrespect of d/Deaf culture. One overarching theme of negative interactions was a lack of understanding of the d/Deaf community, resulting in perceived lack of empathy and respect for d/Deaf patients. Oftentimes, a perceived lack of respect may lead to distrust and frustration, healthcare avoidance, and poor health outcomes.

Curricular suggestions

Our interviews identified instruction in how to correctly utilize an ASL interpreter, awareness of d/Deaf culture and potential bias, awareness of important modifications to exams for differently abled people, and the knowledge of different communication methods and how to help patients access these methods during medical encounters as being essential knowledge for health care providers. By being inclusive of d/Deafness as a unique cultural experience, we can increase awareness and visibility among healthcare providers, leading to better care of the d/Deaf population.

Based on these findings, recommendations for healthcare provider school curricula are to include a discussion of the social determinants of health and psychosocial/cultural experiences of the d/Deaf population. These recommendations are consistent with LCME requirements of diverse cultural competence, healthcare disparity education, and communication skills practice (Liaison Committee on Medical Education, 2020). Healthcare students should reflect on how deafness impacts patient care and health in a broader context. General provider-patient communication skills should be taught alongside methods to communicate with patients with sensory disabilities. Given that medical school curriculums tend to be very packed, this might be a good way to introduce awareness into the curriculum. Rather than focusing on adding whole sessions, schools could be more inclusive by normalizing teaching the modifications to the history and physical exam that may be made to better accommodate d/Deaf and other differently abled patients. Information on utilizing interpreters correctly should be provided prior to students engaging with interpreters; it appears that at least some practicing providers may struggle with this skill in general, and thus preclinical

instruction may help minimize the impact of observing incorrect habits. Finally, schools are already teaching critical thinking skills – encouraging students to use these same skills to challenge their own potential biases around the d/Deaf population would be a worthy and helpful use of these skills.

Conclusion

d/Deaf patients continue to face barriers to healthcare due to communication difficulties, poor awareness among healthcare providers, and accessibility concerns. d/Deaf patients voiced the need for compassionate, collaborative healthcare providers that are educated on d/Deaf patient needs. The experiences and opinions shared in this project support the inclusion of social determinants of health and psychosocial and cultural experiences of the d/Deaf population into healthcare professional curriculums as a solution to these barriers.

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Disclosure statement

The authors report no conflicts of interest. Data from the initial survey was presented in poster format at Best Practices in Health Sciences Education Conference 2021, University of Minnesota.

Footnotes:

1. We use the term d/Deaf to be inclusive of people who both identify in the Deaf community as well as people who identify as deaf (hard of hearing, with English as their first language. These individuals may lipread and/or use hearing aids.)
2. We used the term 'regular doctor' intentionally to refer to a primary care doctor. As noted above, health literacy is a challenging issue for many d/Deaf individuals, and in our screening of the survey

process, the term primary care doctor was identified as potentially confusing for this population.

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Supplemental information: Survey

Disclaimer

The information you enter here is confidential and anonymous. In this survey “d/Deaf population” includes profoundly hard of hearing or d/Deaf persons. This survey is gathering data on how well doctors are addressing the needs of the d/Deaf community. If a question does not apply to you, please leave the question blank. This survey will take 15 minutes or less to finish.

Demographics

1. What is your zipcode?
Type in zipcode (ruca codes analysis)
2. What year were you born?
 - a. Before 1929
 - b. Between 1930-1939
 - c. Between 1940-1949
 - d. Between 1950-1959
 - e. Between 1960-1969
 - f. Between 1970-1979
 - g. Between 1980-1989
 - h. Between 1990-1999
 - i. Between 2000-2010
 - j. Prefer not to answer
3. What was your sex at birth?
 - a. Female
 - b. Male
 - c. Intersex
 - d. Prefer not to answer
4. Which of the following describes your race (check all that apply)?
 - a. White (German, Irish, English, Italian)
 - b. Black or African American
 - c. American Indian or Alaska Native
 - d. Chinese
 - e. Filipino
 - f. Asian Indian
 - g. Vietnamese
 - h. Korean
 - i. Japanese
 - j. Other Asian
 - k. Native Hawaiian
 - l. Samoan
 - m. Chamorro
 - n. Other (specify)
 - o. Prefer not to answer
5. Which of the following describes your ethnicity?
 - a. Not of Hispanic, Latino, or Spanish origin
 - b. Mexican, Mexican Am., Chicano
 - c. Puerto Rican
 - d. Cuban
 - e. Other Hispanic, Latino, or Spanish origin
 - f. Prefer not to answer
6. What is your best estimate of the total yearly income for your household, before taxes?
 - a. \$0 – \$24,999
 - b. \$25,000-\$49,999
 - c. \$50,000-\$74,999
 - d. \$75,000-\$99,999
 - e. \$100,000 or more
 - f. Prefer not to answer
7. What is the highest level of school you have completed?
 - a. Less than high school degree
 - b. High School Graduate/GED
 - c. Some College, No Degree
 - d. Associate Degree
 - e. Bachelor's Degree
 - f. Master's Degree
 - g. Professional School Degree
 - h. Doctoral Degree
 - i. Prefer not to answer
 - j. Don't Know
8. Do you use a cochlear implant?
 - a. Yes
 - b. No
9. If yes, how long have you used a cochlear implant?
 - a. 1 month
 - b. >6 months

- c. >1 year
d. >2 years
e. > 5 years
10. Do you use any other assistive hearing technology such as hearing aids, FM systems, loop systems, accessible telephones/videophones, etc.?
a. Yes
b. No
11. If yes, how long have you used this assistive hearing technology?
a. <1 month
b. >6 months
c. >1 year
d. >2 years
e. >5 years
12. Which statement best describes you?
a. I was born deaf
b. I become deaf in early childhood (< 5 years old)
c. I became deaf between 5-18 years old
d. I became deaf as an adult (>18 years old)
e. None of the above
f. Prefer not to answer
13. Where was your most recent visit with your doctor?
a. Clinic
b. Emergency Room
c. Urgent Care
d. Specialty Clinic
e. Hospital
f. Home
g. Other
14. What tools were used for communication at this visit? (Select all that apply)
a. In-person interpreter(s)
b. I-pad/videophone interpreters
c. Licensed ASL interpreter
d. Certified Deaf interpreter
e. Other technology
f. Written materials
- g. None
h. Other
15. How do you communicate with your doctor when not in-person? (Select all that apply)
a. Messaging/emailing Video Phone or TTY
b. Licensed ASL interpreter
c. Certified Deaf interpreter
d. Family member interpreter (spouse, parent, sibling, child, etc.)
e. Friend(s) interpreter
f. Does not apply
g. Other
16. Do you have a regular doctor?
a. Yes
b. No
17. How many times have you visited your regular doctor in the last year?
a. 0-1
b. 2-3
c. 4-5
d. 6+
e. I do not have a doctor
18. How many times have you visited your regular doctor in the last two years?
a. 0-1
b. 2-3
c. 4-5
d. 6+
e. I do not have a regular doctor
19. How many times have you been to an urgent care or emergency room in the last five years?
a. 0-1
b. 2-3
c. 4-5
d. 6+
20. How many times have you spent one or more nights in the hospital in the last five years?
a. 0-1

- b. 2-3
- c. 4-5
- d. 6+

21. How do you communicate with hearing people? (select all that apply)

- a. Family member interpreter (spouse, parent, sibling, child, etc.)
- b. Friend interpreter
- c. Licensed ASL interpreter
- d. Certified Deaf interpreter
- e. Lip-reading
- f. Written communication
- g. Videophone or TTY
- h. Other technology:
- i. I do not have someone that interprets for me
- j. I do not frequently communicate with hearing people
- k. Other:

22. What are your preferred methods of communication? (select all that apply)

- a. Family member interpreter (spouse, parent, sibling, child, etc.)
- b. Friend interpreter
- c. Licensed ASL interpreter
- d. Certified Deaf interpreter
- e. Lip-reading
- f. Written communication
- g. Videophone or TTY
- h. Other technology:
- i. I do not have someone that interprets for me
- j. I do not frequently communicate with hearing people
- k. Other

23. Who interprets for you when getting in-person healthcare? (select all that apply)

- a. Family member (spouse, parent, sibling, child, etc.)
- b. Friend(s)
- c. Licensed ASL interpreter
- d. Certified Deaf interpreter

- e. I lip-read as my only form of communication in a healthcare setting
- f. I do not have someone that interprets for me
- g. My doctor knows ASL
- h. Other

Section 2

24. My doctor understands how to communicate with me.

- a. Strongly disagree
- b. Moderately disagree
- c. Slightly disagree
- d. Neutral
- e. Slightly agree
- f. Moderately agree
- g. Strongly agree

25. My doctor understands how to communicate with me using an interpreter.

- a. Strongly disagree
- b. Moderately disagree
- c. Slightly disagree
- d. Neutral
- e. Slightly agree
- f. Moderately agree
- g. Strongly agree

26. My doctor understands how to communicate with me using technology (videophone, tablets, etc.).

- a. Strongly disagree
- b. Moderately disagree
- c. Slightly disagree
- d. Neutral
- e. Slightly agree
- f. Moderately agree
- g. Strongly agree

27. My doctor understands how to communicate with me when I am lip reading.

- a. Strongly disagree
- b. Moderately disagree
- c. Slightly disagree
- d. Neutral

- e. Slightly agree
f. Moderately agree
g. Strongly agree
28. I consider problems with communication when choosing a doctor.
a. Strongly disagree
b. Moderately disagree
c. Slightly disagree
d. Neutral
e. Slightly agree
f. Moderately agree
g. Strongly agree
29. I have not accessed medical care because of problems with communication.
a. Strongly disagree
b. Moderately disagree
c. Slightly disagree
d. Neutral
e. Slightly agree
f. Moderately agree
g. Strongly agree
30. I have had medical questions not answered because of problems with communication.
a. Strongly disagree
b. Moderately disagree
c. Slightly disagree
d. Neutral
e. Slightly agree
f. Moderately agree
g. Strongly agree
31. My doctors explain my health in a way that is easy to understand.
a. Strongly disagree
b. Moderately disagree
c. Slightly disagree
d. Neutral
e. Slightly agree
f. Moderately agree
g. Strongly agree
32. I have felt unsure of my own health conditions because of problems with communication with my doctor.
a. Strongly disagree
b. Moderately disagree
c. Slightly disagree
d. Neutral
e. Slightly agree
f. Moderately agree
g. Strongly agree
33. I feel that I understand my health.
a. Strongly disagree
b. Moderately disagree
c. Slightly disagree
d. Neutral
e. Slightly agree
f. Moderately agree
g. Strongly agree
34. Because I am d/Deaf, I have a higher risk for health problems.
a. Strongly disagree
b. Moderately disagree
c. Slightly disagree
d. Neutral
e. Slightly agree
f. Moderately agree
g. Strongly agree
35. I feel understood by doctors.
a. Strongly disagree
b. Moderately disagree
c. Slightly disagree
d. Neutral
e. Slightly agree
f. Moderately agree
g. Strongly agree
36. I feel respected by doctors.
a. Strongly disagree
b. Moderately disagree
c. Slightly disagree
d. Neutral
e. Slightly agree
f. Moderately agree

g. Strongly agree

37. I feel I can trust doctors.

- a. Strongly disagree
- b. Moderately disagree
- c. Slightly disagree
- d. Neutral
- e. Slightly agree
- f. Moderately agree
- g. Strongly agree

38. Overall, I am happy with my experience with doctors.

- a. Strongly disagree
- b. Moderately disagree
- c. Slightly disagree
- d. Neutral
- e. Slightly agree
- f. Moderately agree
- g. Strongly agree

39. I wish that my doctor could better communicate with me.

- a. Strongly disagree
- b. Moderately disagree
- c. Slightly disagree
- d. Neutral
- e. Slightly agree
- f. Moderately agree
- g. Strongly agree

40. Open-ended question: In your opinion, what are the most important ways to improve your healthcare experience?

OPTIONAL: If you are interested in participating in a paid focused interview on your healthcare experience, please enter your email below.