

COMMUNICATION IN HEALTHCARE SETTINGS: ACCESS AND BARRIERS TO
CARE EXPERIENCED BY DEAF PATIENTS

by

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DEDICATION

To all of the Deaf people who have been part of my life and career: I cannot say how much I have been blessed by “people of the eye.” Thank you for giving me perspective, humility, skills, relationships, and patience. Thank you for allowing me to be an invited guest in your world—I will never be able to explain all the ways it has changed me for the better. May this dissertation serve as a small payment towards the debt of gratitude and love I happily owe.

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ABSTRACT

Deaf persons who use American Sign Language (ASL) as their primary form of communication are members of a cultural and linguistic minority that experiences significant health disparities yet are not recognized as a health disparity population by the National Institutes of Health. Studies have reported ineffective communication in healthcare interactions and reduced access to care experienced by Deaf patients. Requests for sign language interpreters in healthcare encounters are frequently denied, despite federal mandates to provide effective communication. Comprised of three articles, this dissertation investigates the diminished access to communication in healthcare settings experienced by Deaf patients and qualitative research methods when working with Deaf communities.

Chapter One provides an overview of the dissertation purpose along with authorship and statement contributions for each article. Chapter Two features an autoethnographic study which recommends specific research methods and paradigms researchers who can hear should consider when conducting research with Deaf people. Reflections on the process of qualitative data analysis in this context is provided. Chapter Three reports the results in article form from a mixed-method, bilingual, and online survey which received 170 responses from Deaf respondents in 42 states. The survey provides a deeper understanding of the communication barriers experienced by Deaf patients than has been available or documented previously. Chapter Four documents the diminished access to care experienced by Deaf patients as documented in a “secret

shopper” study. Appointment success rates of Deaf simulated patients compared to success rates of simulated patients who can hear, and reasons associated with denials are reported from a field-experiment audit study of a stratified random sample of primary care and general dentistry clinics throughout Idaho. Chapter Five provides a summary of the dissertation findings, action and policy recommendations, planned and completed dissemination of the research results, and areas of future research.

TABLE OF CONTENTS

DEDICATION	iv
ACKNOWLEDGMENTS	v
ABSTRACT.....	vi
LIST OF TABLES	xii
LIST OF FIGURES	xiii
LIST OF VIDEOS	xiv
LIST OF ABBREVIATIONS.....	xv
CHAPTER ONE: INTRODUCTION.....	1
The Dissertation	2
Chapter Two. Begin with Equity in Mind: Reflections and Procedures for People Who Can Hear When Conducting Qualitative Healthcare Research with Deaf Communities.....	3
Statement of Authorship	4
Publication Status.....	4
Chapter Three. “I’m Treated Like I’m Sub-Human”: A Survey of Deaf Patients and Communication in Healthcare.....	4
Statement of authorship	4
Publication Status.....	5
Chapter Four. Interpreters Are “Too Expensive and We Probably Won’t Talk That Much”: An Audit Study of Deaf Patients’ Access to Basic Health Care	5
Statement of authorship	6

Publication Status.....	6
Chapter Five. Conclusion.....	6
CHAPTER TWO: Begin with Equity in Mind: Reflections and Procedures for People Who Can Hear When Conducting Qualitative Healthcare Research with Deaf Communities.....	7
Abstract.....	7
Introduction.....	8
Background.....	10
Sociocultural Realities	10
History of research on, about, and for Deaf people and communities.....	14
Language, Modality, and Interpretation.....	15
Critical and Transformative Epistemology	21
Methods.....	22
Autoethnographic Research Rationale and Methods	22
Situating the researchers	25
Focus of the autoethnography.....	26
Application of Qualitative Data Analysis Method.....	27
Findings of the Autoethnography	30
Reflexivity.....	33
Conclusion and Recommended Research Framework	35
CHAPTER THREE: “I’M TREATED LIKE I’M SUB-HUMAN”: A SURVEY OF DEAF PATIENTS’ NEEDS FOR COMMUNICATION IN HEALTHCARE	38
Abstract.....	38
Objective	38
Study setting.....	38

Study design.....	38
Data collection	38
Principal findings	39
Conclusions.....	39
Introduction.....	40
Methods.....	43
Quantitative Methods.....	44
Qualitative Methods.....	46
Quantitative Results	47
Qualitative Results	56
Discussion	73
Summary of Key Results	73
Legal Obligations and Dilemmas Regarding Interpreter Services	74
Comparison with other studies.....	76
Limitations and strengths.....	76
Implications.....	77
CHAPTER FOUR: Interpreters are “too expensive and we probably won’t talk that much”: An audit study of Deaf patients’ access to basic health care	78
Abstract.....	78
Key Points.....	80
Introduction.....	81
Methods.....	83
Design and Setting	84
Measures	86

Statistical analysis.....	87
Results.....	87
Discussion.....	91
CHAPTER FIVE: CONCLUSION.....	96
Conclusion and Discussion.....	96
Implications & Recommendations.....	99
Data Dissemination & Future Research Directions.....	107
REFERENCES.....	110
APPENDIX A.....	129
APPENDIX B.....	131
APPENDIX C.....	138
APPENDIX D.....	143

LIST OF TABLES

Table 2.1	Comparative Linguistics: ASL and English	16
Table 3.1	Demographic and identity according to healthcare access and appointment communication variables	49
Table 3.2	Demographic, healthcare access, accommodation and communication, and satisfaction factors associated with foregoing care, consistency requesting healthcare provision of interpreters, primary mode of communication at healthcare appointments, and satisfaction with medical care among users of ASL.....	54
Table 4.1	Demographic and call related factors overall and by success status for securing an appointment by Deaf simulated patients	89
Table 4.2	Demographic and call-related factors associated with having an interpreter-related reason for unsuccessful attempt at accessing health care among Deaf simulated patients.....	91
Table A.1.	CRediT — Contributor roles taxonomy	130

LIST OF FIGURES

Figure A	Page 1 of 2 Questions to Ask When Considering Research with Deaf Communities.....	36
Figure B	Page 2 of 2 Questions to Ask When Considering Research with Deaf Communities.....	37
Figure C	Deaf patients’ unmet needs and expectations for communication in healthcare settings: Themes, sub-themes and properties	57
Figure D	Sampling Procedure and Reasons for Clinic Exclusion	85
Figure E	Outcomes of New Patient Appointment Requests.....	88
Figure F	LCME Cultural Competence and Health Care Disparities Curriculum Standard 7.6 copyright 2020, Association of American Medical Colleges and American Medical Association	106
Figure G	Visual Abstract of Audit Study Findings.....	144

LIST OF VIDEOS

Video 1	Survey Quote V.1 in ASL.....	58
Video 2	Survey Quote V.2 in ASL.....	59
Video 3	Survey Quote V.3 in ASL.....	60
Video 4	Survey Quote V.4 in ASL.....	61
Video 5	Survey Quote V.5 in ASL.....	62
Video 6	Survey Quote V.6 in ASL.....	63
Video 7	Survey Quote V.7 in ASL.....	64
Video 8	Survey Quote V.8 in ASL.....	65
Video 9	Survey Quote V.9 in ASL.....	66
Video 10	Survey Quote V.10 in ASL.....	67
Video 11	Survey Quote V.11 in ASL.....	68
Video 12	Survey Quote V.12 in ASL.....	69
Video 13	Survey Quote V.13 in ASL.....	70
Video 14	Survey Quote V.14 in ASL.....	72

LIST OF ABBREVIATIONS

ADA	Americans with Disabilities Act (and ADA As Amended)
ASL	American Sign Language
CDI	Certified Deaf Interpreter
CRediT	Contributor Roles Taxonomy
CDHH	(Idaho) Council for the Deaf and Hard of Hearing
DOJ	U.S. Department of Justice
ED	Emergency Department
HIPAA	Health Insurance Portability and Accountability Act
HHS	U.S. Department of Health and Human Services
ISU	Idaho State University
LEP	Limited English Proficiency
NIH	National Institutes of Health
NIMHD	National Institute on Minority Health and Health Disparities
OCR	Office of Civil Rights (division of HHS)
PI	Principal Investigator
SP	Simulated Patient
VRI	Video Remote Interpreting

CHAPTER ONE: INTRODUCTION

Deaf people who use American Sign Language (ASL) as their primary mode of communication have reported anecdotally the lack of accessible communication when receiving health care. So frequent is this experience that the National Association of the Deaf characterizes health care as “routinely inaccessible.”¹ Yet, in less than three months (at time of this writing) the law implemented to prevent discrimination against persons with disabilities will have been in existence for 30 years. The Americans with Disabilities Act (ADA) was passed in 1990, and required all government entities, businesses, and nonprofit organizations that serve the public to provide effective communication to all persons, including those who use ASL to communicate.² In the 2013 revised final regulations implemented by the ADA, the Department of Justice (DOJ) Civil Rights Division Disability Rights Section published “ADA Requirements: Effective Communication” that further specified: “...an interpreter generally will be needed for taking the medical history of a patient who uses sign language”(pg. 4).³ Still, reports of discrimination against Deaf patients and inaccessibility to healthcare are regularly reported to a variety of entities, including state agencies serving Deaf persons.⁴

Deaf patients report feelings of fear, mistrust, and frustration in healthcare encounters and perceive that the main communication barrier is the lack of provision of sign language interpreters.⁵ Without effective communication, Deaf patients may be unable to form a strong relationship with their healthcare provider¹ or share important details regarding their medical history.⁶ Deaf patients may leave healthcare appointments

without a clear understanding of their diagnosis⁷ or the importance of the treatment prescribed by their provider.⁸

Data currently available regarding the healthcare and communication experiences of Deaf patients is sparse and may be incomplete or incorrect. As a whole, data reflecting experiences of Deaf people are absent from health surveillance research, as much of this research is conducted via random-digit-dial phone surveys which categorically exclude Deaf people that use videophones.⁹ Due to previously existing technical restrictions, Deaf people have been unable to anonymously complete or submit narrative survey responses in ASL, potentially limiting the number of respondents willing or available to participate.

Studies have been conducted by investigators unable to fluently communicate in ASL who fail to provide sign language interpreters, resulting in incomplete data. Some researchers do not recognize that “there is no neutral position from which to translate” and that interpreters become part of the creation of knowledge.^{10(p175)} Others have provided unqualified and/or ad hoc interpreters who render inaccurate interpretations.¹¹ They may fail to recognize that Deaf people are members of a sociolinguistic minority,¹¹ necessitating reflexivity and cultural humility on the part of the researcher,¹² without which accurate data on the health outcome and access disparities experienced by Deaf people cannot be compiled.

The Dissertation

The dissertation is presented in three stand-alone empirical articles. Upon completion of the dissertation defense, the articles presented in chapters three and four will be submitted for publication in peer-reviewed, MedLine-indexed journals. The article presented in Chapter Three is currently under review (as of July 2020) by a peer-

reviewed Medline-indexed journal and the article presented in Chapter Four has been submitted for review to a Medline-indexed journal. In the following dissertation chapters, literature across three main areas was examined: 1) Access to communication and communication barriers experienced by Deaf persons in healthcare settings, 2) Diminished access to healthcare experienced by Deaf people, and, 3) the nature of qualitative research conducted by etic researchers with or for Deaf communities and best practices.

In this section, I provide an overview of the chapters following and brief summaries of each study presented. Articles presented in the chapters were created by more than one author. As such, an statement of authorship is provided for each chapter, in the Contributor Roles Taxonomy (CRediT) format.¹³ A table summarizing the CRediT taxonomy classifications is available in Appendix A.

Chapter Two. Begin with Equity in Mind: Reflections and Procedures for People Who Can Hear When Conducting Qualitative Healthcare Research with Deaf Communities

The article in Chapter Two features an auto-ethnographic study presented as a conceptual manuscript that examines elements of Deaf epistemology, adoption of a critical transformative epistemology paradigm in order to conduct socio-cultural and linguistically appropriate research with Deaf communities, issues that arise when people who can hear conduct research with Deaf subjects, and features of a novel survey method employed to collect qualitative data in ASL. These topics are explored through the lens of researchers who can hear against the backdrop of design, implementation, and analysis of

a mixed-methods survey instrument that sought to document communication experiences, preferences, and needs of Deaf patients in healthcare settings.

Statement of Authorship

Elizabeth Schniedewind, lead and corresponding author; Campbell McDermid, second author; Nicole Hayes and Ronnie Zuchengo, contributors.

Writing – Original Draft: E.S. and C.M.; *Writing – Review and Editing:* E.S. and C.M.; *Methodology:* C.M. and E.S.; *Formal Analysis:* C.M. and E.S.; *Investigation:* E.S. and C.M.; *Data Curation:* E.S., C.M., N.H., and R.Z.; *Visualization:* E.S. and C.M.

Publication Status

We will first submit this article to either *Qualitative Health Research* or the *Disability and Health Journal*. After selecting the journal, we will edit the article to comply with the appropriate author guidelines prior to submission.

Chapter Three. “I’m Treated Like I’m Sub-Human”: A Survey of Deaf Patients and Communication in Healthcare

Chapter Three is an article reporting findings of a mixed-method online survey from the analysis of the quantitative and qualitative data collected. The Deaf Healthcare Survey was a bilingual online survey which received 170 responses from respondents in 42 states and provided a deeper understanding of the communication barriers experienced by Deaf patients than has been available or documented previously. Narrative responses were submitted in both written English and in ASL as video responses.

Statement of authorship

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Publication Status

The journal we have identified for first submission of this article is *Health Services Research*. The abstract is structured in accordance with their author guidelines, and an additional requirement of a “What is Known/What This Study Adds” section is included.

Chapter Four. Interpreters Are “Too Expensive and We Probably Won’t Talk That Much”: An Audit Study of Deaf Patients’ Access to Basic Health Care

The article in Chapter Four documents the diminished access to care experienced by Deaf patients. A field-experiment audit study of a random, stratified sample of primary care and general dentistry clinics throughout Idaho was conducted. Four

^a Summary of research findings and data presentation in ASL for the articles presented in chapters three and four will not be available until manuscripts have been accepted as an article in press to ensure consistency between the final proof and information in ASL.

Simulated Patients (SPs) who can hear and four Deaf SPs followed a call script while requesting a new patient appointment. If offered an appointment, Deaf SPs also requested that a sign language interpreter be provided. Results detailed appointment success rates and reasons associated with denials.

Statement of authorship

Elizabeth Schniedewind, lead and corresponding author; Ryan Lindsay, second author; Steven Snow, third author. William Andrew, Bekki Boslau, John Coles, Carl Siebert, and Davina Snow, contributors.

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Publication Status

This article is currently under review by *JAMA Network Open*. Submission date: April 30, 2020. The abstract is structured in accordance with their author guidelines, and an additional requirement of a “Key Points” section is included.

Chapter Five. Conclusion

Chapter Five details findings of the dissertation, recommendations, completed and future dissemination plans, data presentation in ASL, and directions for future research.

CHAPTER TWO: Begin with Equity in Mind: Reflections and Procedures for People
Who Can Hear When Conducting Qualitative Healthcare Research with Deaf
Communities

Abstract

The following is an autoethnographic account of the process of design, study implementation, and reflection of research on the Deaf community. Its genesis was the creation of a mixed-method study that solicited input from Deaf users of ASL in the United States regarding their experiences with and preferences for communication and access in healthcare settings. To determine the method of data collection and analysis of respondent narratives, the authors of this study underwent a process of reflective contemplation and review of the literature. This reflective process considered the numerous concerns that have been raised regarding the lack of Deaf representation and voice in research, and many gaps and problematic assumptions of past endeavors were reviewed. This introspective approach is essential given the etic nature of the mixed-methods study, as neither researcher is Deaf nor a native signer of ASL.

Recommendations made include the application of a research paradigm, questions for researchers, specific methods of data collection that complement and are consistent with capturing a visual-spatial language, recruitment and retention of a critical mass and diverse representation of Deaf co-researchers and community partners, and the involvement of Certified Deaf Interpreters for research about or for the Deaf community.

Introduction

The relationship between members of the Deaf² community and healthcare researchers has been characterized as “disconnected”¹⁴ and one that produces research that is “for them not for us.”¹⁵ One cause of this may be that hearing³ researchers often fail to recognize the cultural aspects of the Deaf community¹⁶ and, instead, rely on a highly medicalized approach¹⁷ that excludes or can be ethically abusive¹⁶ to the population studied. For example, it has been noted that Deaf people have been systematically excluded from public health surveillance efforts because of the reliance on data collection methods that require the ability to hear in order to provide a response¹⁸ and are under-represented in clinical trials due to inaccessible recruitment procedures.¹¹

Further exacerbating this lack of a voice is the practice of the National Institutes of Health (NIH) and the National Institute of Minority Health and Health Disparities (NIMHD) who do not fund research on Deaf communities as a recognized health disparity population.¹⁹ This is despite wide recognition that they are a cultural and linguistic minority that experiences significant healthcare disparities in outcomes, literacy, and access.^{14,20–22} It is an irony not lost on members of the Deaf community that, although many do not consider themselves to be disabled,²³ the institute that typically

²Deaf – We use this term to indicate the group of persons who have a sociological affiliation with a Deaf community and/or identify as members of Deaf culture. This affiliation is based on a shared use of sign language and, often, experiences of oppression.¹⁹⁰ The identification is not based on hearing acuity or the results of audiological measurements.²⁰ We use the term Deaf inclusively,¹⁹⁰ to apply to those who identify as Deaf, deaf, deafblind, deafdisabled, hard of hearing, late-deafened and hearing impaired, and in recognition of the fact that identity may not be static over time.¹⁹¹

³Hearing – This term refers to persons who can hear that do not have a sociological affiliation with a Deaf community or identify as members of Deaf culture. Persons who are hearing are often unaware that their hearing acuity and use of speech constitutes part of their identity.¹⁹² There are some individuals who are able to hear, but are not considered to be hearing within Deaf communities, most notably Children of Deaf Adults.¹⁹³

funds Deaf-focused is the National Institute of Deafness and other Communication Disorders [emphasis ours] and was, even at inception, criticized by members of the Deaf community as prioritizing research with a medicalized approach.²⁴

Within the context of a medical model of disability,²⁵ healthcare professionals employ evidence-based practice to, ostensibly, promote the best possible health outcome for patients. Consider, however, research that fails to accurately portray health outcomes of Deaf patients, and how this evidence is applied in practice. It is reasonable to believe that the relationship between Deaf patients and providers, historically steeped in fear, mistrust, and experiences in inadequate communication²² is further negatively impacted. The resulting, although potentially inadvertent, lack of culturally competent care can constitute a barrier to accessible health services²⁶ and can result in diminished participation in preventative services⁹ and a perpetuation of limited access to health information and ineffective healthcare education for members of the Deaf community.²⁷

Despite being well-intentioned, hearing researchers who fail to recognize the potential impact of the research paradigm they employ to frame issues, the influence of their own views and positionality, and the privilege afforded to them as a result of their hearing acuity may instead cause harm. In this article, we aim to highlight the impact of these three aspects of the research process and in so doing work to deconstruct and rebuild the process. The use of analytic autoethnography in this context articulates the criteria we applied during our self-evaluation as we considered our own appropriateness as researchers investigating issues of importance to the Deaf community, and makes this criterion available for other hearing researchers. We explore three key themes: (a) sociocultural realities and philosophical constructs to be considered by hearing

researchers; (b) impact of language, translation/interpretation, data collection modalities, and the researcher; and (c) analysis and reflections of qualitative methods and procedures employed while conducting a mixed-methods survey with the Deaf community.

Background

Sociocultural Realities

Ontological Aspects of Deaf Culture

Deaf people, who are bimodal and bilingual users of language, represent a unique linguistic population in the United States. They have access to two different sensory-motor systems when processing language, and there is evidence that the organization of the brain is structured in a different, yet no less effective, manner.²⁸ When one also considers that Deaf people move throughout society and their lives attending to different information, and yet live within a framework of the majority population, it stands to reason that these “people of the eye”,²⁹ would have different experiences and values regarding healthcare encounters and research conducted on themselves and members of their community.

As a result of participation in and an affiliation with Deaf communities and/or an identification as a member of Deaf culture, common beliefs may develop and experiences that are similar in nature may be noted. For example, filial bonds may be based on community as opposed to biological bonds,³⁰ as enculturation of Deaf individuals may occur when they identify as a member of the community while attending a residential school for the Deaf.³¹⁻³³

A positive perspective of the Deaf experience and way of being regards being Deaf as a reason for celebration,³⁴ as this can give rise to the acquisition of fluent sign

language, the use of which is highly valued.³³ Sign language is regarded as a contribution to the wider society and, if hearing people learned sign language, the quality of their lives would be improved.³⁴

The Deaf community regards itself as deeply-connected globally,³⁵ not bounded in one geographically delineated location,³³ but as a tightly knit³⁶ and collectivist^{32,37-39} community that emphasizes social relationships⁴⁰ and has shared social, moral, and sensorial experiences across country borders.³⁵ The collectivist nature of the Deaf community may encourage a consensus decision-making process as a “live together, succeed together” approach^{38,41} that also includes an expectation to contribute to the community as one is able without an expectation of reward,⁴¹ but that ascribes status and identity “by one’s connections within the group.”⁴²

Even when rejecting the false binary of Deaf vs. hearing, some experiences and beliefs of hearing people in America are appropriate to examine as a contrast to the perspective of Deaf people and members of Deaf communities. The culture of the researcher can unknowingly serve as a “contact lens that affects the individual’s perceptions of visual stimuli all of the time.”⁴³ Although the culture of hearing people in the United States is not regarded as a monolith, the difference between a highly individualistic community where decisions are made by the majority and success is achieved independently^{32,39,42} and the beliefs held by Deaf people and their communities is significant.

These differing ontological realities leads to the question, “Is there an epistemology of Deaf people?” Given the differences in language and culture and overall experience of being, the answer is, “How could there *not* be?” The plethora of hearing researchers who

have not reflected on this epistemological question then speaks directly to a crisis in representation as noted in the literature on ethnography.⁴⁴

Deaf Epistemology

Before looking at what the literature says on an epistemology that is emancipatory in relation to the Deaf community, it is perhaps important to first understand the various aspects of epistemology and provide a definition. In a discussion of racism at the level of civilization, the components of epistemology have been outlined as “the level that encompasses the deepest, most primary assumptions about the nature of reality (ontology), the ways of knowing that reality (epistemology), and the disputational contours of right and wrong or morality and values (axiology)-in short, presumptions about the real, the true, and the good.”^{45(p6)} In the emancipatory-transformative paradigm, methodology would also be included.⁴⁶ These definitions become important throughout this document as we outline differences in the ontology, epistemology, and axiology of the Deaf community in relation to the broader, non-Deaf or hearing civilization in which they live.

At the level of axiology, a critical epistemology requires recognition of differences in value systems, specifically who decides what knowledge is of value and valid.¹⁶ There is also a need to situate the researcher in terms of the community and for that individual to demonstrate cultural competency as well as linguistic competency when working with Deaf people.¹⁶

In terms of ontology, what history has shown us is that when researchers from the majority culture (hearing) decide what constitutes knowledge, they have turned to standardized tests designed for people who can hear or tests which include small samples

of Deaf individuals and described as representative of the community.¹⁶ When majority-culture researchers employ assessments that have been interpreted, the validity of the instrument may be compromised⁴⁷ and there is a high risk of bias,⁴⁸ which may result in erroneous conclusions based on inaccurate data.

The broader framework for this study, the paradigm or epistemological assumptions, fall within a hybrid perspective of critical theories and post structuralism as defined in the literature.⁴⁹ Within this paradigm, it is recognized that the construction, implementation, and the later interpretation of research projects is a constructivist process that is situated within a context,⁴⁹ which is an important consideration when doing qualitative research involving Deaf people. In a postmodern paradigm, the attempt of this research is to identify and deconstruct a grand narrative.⁴⁹ In this instance, the grand narrative is that of Deaf people as disabled and the hegemonic belief that the research process is conducted on Deaf people and within an unbiased epistemology. It is within that paradigm that the research project was designed and later interpreted in an active process between the researchers and the Deaf community. The ultimate goal is to “deconstruct and rebuild practice.”^{49(p690)}

Such an epistemology attempts to address the crisis in representation and how is it possible to represent the voice of Others,⁴⁴ especially in a research process which is etic, as the researchers are not Deaf. It also recognizes that in any study, the researcher’s subjectivity completely shapes the research design and later analysis. As noted in the literature, while conducting research, “There is so much to think about; so many conscious decisions to be made.”^{50(p254)}

As an example of educational research approaches that recognize an epistemology of Deaf people, strategies employed with Deaf learners that are consistent with a Deaf-centered approach can include maximizing the amount of visual information or visual mnemonic devices possible through the use of manipulatives,⁵¹ closed captioning in videos, a white board and things like graphic organizers.⁵² It could also mean making use of more exophoric reference to objects in the environment, through pointing behaviors.^{53,54} At the same time, it means limiting competing visual stimuli.⁵³⁻⁵⁵

History of research on, about, and for Deaf people and communities

There are a multitude of reasons that Deaf communities may have a negative perspective of research and researchers, including the lack of recognition for an epistemology of the Deaf. Deaf people have reported that it is tiring to have researchers come into their community, perform tests and collect data when the results are not shared and they do not see these researchers give back to their community.^{14,22,56} Further, the literature identified profound deficits in the design of studies on the Deaf including: researchers' promotion of a "medical model" of Deaf people;¹⁴ portrayals of Deaf people as inferior, unintelligent, and disabled;⁵⁷ systematic exclusion from research outcomes⁵⁸ and a history of elimination of Deaf people as a goal, currently promoted in the use of technology and genetic engineering.¹⁴

One cause is the lack of recognition for ASL. Research designed to document the experiences of Deaf individuals in healthcare are commonly found that rely on information collected in written English. For example, a survey administered in 1995 regarding the sexual health knowledge of Deaf and hard of hearing college students reported results from 134 participants. Collecting data through the use of text surveys

alleviates concerns that come with in-person processes such as asynchronous completion of the survey and anonymity, which is well-suited to the people's busy lives.⁵⁷ However, this survey was, as many others,^{47,48} conducted entirely in written English and although it is noted as a limitation, the psychometric properties of the instrument were not evaluated, suggesting that it was possible that participants drew incorrect conclusions from the survey items.⁵⁹ Deaf people have repeatedly explained that they feel better understood when they can use their first language rather than a written form of their second language when asked to participate in research.³⁶ Using surveys, therefore, may fail to capture the views of monolingual ASL users, as survey item comprehension becomes suspect, and open-ended questions would require answers in the second language of the respondents to be reliably reported.³⁶

Language, Modality, and Interpretation

There are fundamental differences between a visual and spatial language such as ASL and English, an auditory and linear language. The unique features of ASL, coupled with the mode of transmission can have a recognized impact on the process of and conclusions made in research.⁶⁰⁻⁶² Likewise, for many hearing researchers not fully fluent (an undefined measurement, at best) in sign language, the services of interpreters and translators may be necessary, but not fully effective or accurate, even when interpreters are qualified.^{14,57}

For hearing researchers, a basic understanding of the grammatical differences (see Table 2.1) as well as pragmatic differences is merited.

Table 2.1 Comparative Linguistics: ASL and English

		English	ASL
Syntax	English usually follows a subject-verb-object word order (SVO). ASL can follow an SVO order but also topic-comment, ⁶³ verb initial and final (verb sandwich) ⁶⁴ and either OSV or SOV ⁶⁵	“I am going back to the store where we bought the coffee from Columbia.”	REMEMBER LAST WEEK STORE HAVE COFFEE COLUMBIA, I GO AGAIN.
Copula verb	English makes use of a copula verb “to be” while ASL makes use of structures such as a head nod ⁶⁵ or the sign HAVE ⁶⁶	“Susan is a doctor.” “There will be a meeting tomorrow at 10 for the department.”	SUSAN head nod DOCTOR TOMORROW TIME 10, MEETING DEPT HAVE.
Compounds	Signs or words can be compounded to make new words ⁶⁷	Hand + made = “handmade”	SLEEP + CLOTHES = pajamas
Phrasal verbs	English makes use of phrasal verbs, a verb plus a preposition while ASL makes use of only a verb ⁶⁸	“She came into the store.”	SHE ENTER STORE
Pronouns	English sentences make use of a variety of pronouns as does ASL though ASL drops pronouns more often ⁶⁹	“ I saw Bob at the table, so I gave the book to him .”	SAW TABLE (on right) BOB SIT (on the right), SO BOOK GAVE-to-the-location.
Classifiers	ASL includes signs that have multiple functions and meanings such as indicated the size or an object or its location in space ⁶⁸	“I put the coffee cup on the coffee table.”	COFFEE TABLE Classifier:B (show where the table is in space), CUP, reposition the table Classifier:B and place Classifier:C on top.
Inflection	English makes use of raised vocal inflection to indicate a “yes/no” question and lowered inflection to indicate a “wh” (who, what, where) question. ASL makes use of non-manual signals such as raised eyebrows and a forward head tilt to signal a “yes/no” question and lowered eyebrows (squint) and a head tilt back for “wh” questions ⁶³	“Are you going to the store?” “Where are you going?”	GO STORE? (with eyebrows raised and leaning forward) YOU GO WHERE? (with eyebrows squinted and leaning slightly back).
Synonyms	ASL and English can vary in terms of words and signs that act as synonyms for each other.	“Have you visited Washington, DC?” “Have you been to Washington, DC?”	TOUCH FINISH Washington DC? SEE FINISH Washington DC?
Homonyms	English has words that sound similar but have different meanings as ASL has signs that look similar but have different meanings.	To, too and two	ISLAND INTEREST

Superordinate	English and ASL can differ in terms of their use of superordinate terms	“I bought a new vehicle. ”	I BUY CAR NEW
Conjunctions	ASL and English can differ in terms of words and signs used as conjunctive devices ⁷⁰	“For, and, nor, but, or, so, yet”	FRUSTRATE, HIT, WRONG

As it relates to pragmatics, differences in the implications of the ASL signs TO THINK and TO FEEL have been noted⁷¹ when compared to their English equivalents “think” and “feel.” For example, an English speaker may say “I feel that it will rain tomorrow,” or “I think that it will rain tomorrow,” while a Deaf signer may sign FEEL TOMORROW RAIN or THINK TOMORROW RAIN. Where the English speaker used “think” they later explained that it could be either strongly or weakly believed to be true, while the use of “feel” was even weaker. Deaf signers, however, associated a weaker or more false belief with THINK and said that when they signed FEEL, they held a stronger belief that the event would happen.⁷¹

This pragmatic difference is also evident in accurate interpretations from English to ASL. In a study of interpreters qualified to provide services in a legal setting, interpreters appropriately changed the function of an English utterance to a command and rendered an ASL interpretation of a yes/no question that explicated the expected response in English when interpreting the spoken English question “And is your teacher in court today?” by including “POINT WHERE” in ASL.⁷² In another study,⁷³ Deaf co-analysts agreed that an interpreter correctly interpreted the English utterance “She then asked me where I was at the Deaf rally for ASL rights...” to include “WHY YOU SKIP/MISS RALLY” in ASL. One study noted that an interpreter asked for clarification of the “usual risks”^{74(p165)} or side effects of anesthesia believing the Deaf participant may not know.

The modality of sign language impacts data collection and the analysis of data in research. ASL data are not available in written form, so researchers have taken the content of the visual-spatial language and repackaged it into a form that standard analysis tool can handle. But this approach does not acknowledge the nature of a topic-comment language, and the role of multi-layered expression that requires space and an understanding of the facial grammar used to be understood as a whole.¹⁰ Because of the issues stated, thoughtful researchers have employed a number of strategies to avoid perpetuating the “invisibility” of ASL when translated. One approach is to delay translation as long as possible, code qualitative data in ASL on video, and only translate relevant portions that will appear in English-based publications.¹⁴

Typically face-to-face methods, including focus groups and individual interviews have been used when collecting qualitative data with ASL users.⁵⁸ This usually involves filming groups with up to three cameras and then integrating all camera angles.^{14,60} Data collected in ASL cannot be edited in the same way a printed text can.⁶¹ When editing ASL video texts, transition phases between utterances appear unnatural unless the signer’s hands are brought to a neutral space, which complicates the ability to piece videos together and will sometimes necessitate repeated filming.⁶²

Anonymity is of significant concern when conducting research with and about Deaf communities, largely due to the modality of signed languages and the use of videotaping. It is not possible to preserve the language data from a signing individual and also conceal their identity.⁶² Video recording can lead to “greater risks for breaches of confidentiality in contrast to participants who provide data through writing, voice, or other modalities where their faces are not captured on film.”^{24(p166)} Where software is

used to obfuscate facial features, it may not mask “characteristic signing styles that may lead to inadvertent identification of the participants.”^{24(p166)} Worse, obscuring a participant’s face also removes grammatical information from their signing,²⁴ such as raised eyebrows for a Yes/No question. Although those who conduct research with Deaf persons may be ethical, concerns may be raised from institutional review boards, and Deaf people can be discouraged from participating in research.^{57,75}

When hearing researchers must rely on a third-party to interpret for them during data collection, a valid concern has been raised regarding lack of skill in the interpreting or translating process. One study found that novice and expert interpreters omitted anywhere from 32% to 53% of the comments a signer made.⁷⁶ More recently, the national certification body for sign language interpreters, the Registry of Interpreters for the Deaf (RID), reported only a 27% pass rate for the generalist interpreter certification examination in 2018 and a lower 25% in 2016 and 2017.^{77,78} In two studies of interpreters that provide services in educational settings, out of a possible score of 5 on a performance assessment specifically constructed for educational interpreting, only 44% interpreters in the first study⁷⁹ scored 3.5 or above and only 38% in the second study.⁸⁰ Using the same assessment, a similar study found even lower scores, documenting a mean score of 2.⁸¹

When hearing interpreters were compared to Deaf interpreters working in British Sign Language (BSL), several significant differences in the way information was presented to the audience was noted.⁸² The Deaf interpreters made more use of a “participatory perspective” where they became one of the characters in the story and acted out the character’s behavior.^{82(p104)} Interpreters included different types of enrichments, such as temporal or locational to show how an action occurred or its

location. Visual representations are cohesive and present information simultaneously when rendered by Deaf interpreters while hearing interpreters presented information piece meal, much like a puzzle, as noted in an interview with one Deaf participant.⁸²

Languages are inherently metaphorical, and metaphors do not translate well. In English, an interpreter could not directly translate the phrase “I invested a large part of my life into that company” or “We hit a rocky road in our marriage and ended up on different paths” without breaking from form to convey the meaning in ASL. In a similar vein, ASL handshapes have metaphorical meanings that are not directly conveyed in a literal translation. While in English a “thumbs up” may have a positive meaning, the same handshape used to create signs like NOT and DENY and BLAME are considered negative. A “perfect translation” is generally not possible¹⁴ and can be undesirable, as the act of translating can remove culturally-rich information.⁶¹

And, more broadly, should interpreters and translators be employed in the research process? In many US states, the profession of sign language interpreting is unregulated, requiring neither a license or a quality assurance evaluation⁸³ and a hearing researcher would be unable to verify the skill level of the interpreter hired. Even when skilled interpreters are hired, Deaf participants note the need to clarify information.⁸⁴ Deaf participants in research have stated that they would prefer to communicate directly with researchers.⁸⁴ Further, interpreters and translators “form part of the process of knowledge production.”¹⁰ Yet in many studies conducted by hearing researchers, the qualifications of an interpreter or “expert” in sign language may not be divulged.⁸⁵

Critical and Transformative Epistemology

The differences in epistemology and concerns about hearing researchers studying the Deaf either through English or with an interpreter led to a decision to adopt a critical and transformative epistemology research paradigm as conceptualized by Mertens.⁴⁶ The role of researchers was pondered in the furtherance of social justice and human rights⁴⁶ and how we can continue to recognize and respond to diversity. Such an epistemology recognizes issues of power and ethical responsibility to recognize differences in culture. The goal is to develop trust in the process and work towards social change.⁴⁶ Throughout, the researchers must ask themselves, “Am I the right person to do this research?”

Other authors have outlined steps to honor a Deaf epistemology and these informed many of the decisions in this study. A second important goal guiding the mixed-methods study design was the application of community-engaged research, which either seeks to establish or further build upon trusting relationships between researchers and community members and/or community organizations.⁸⁶ The research process should be iterative in nature and include a mixed-methods approach constructed from a transformative paradigm.¹⁷ To facilitate a transformative epistemology, there must be an interactive relationship between the community and researchers.¹⁶ It has been argued that there needs to be a ubiquitous presence and involvement of Deaf people at every level and phase of the research process,^{14,61,87} a critical mass of Deaf participants with the majority of the members on the research team being Deaf,¹⁴ and that participants should be told the names of all of the researchers or those who will see their information, including Deaf raters.²⁴

Consideration should be given to the obligation of researchers to report back to the community and provide recognition that the Deaf community has a strong tradition of reciprocity and collectivism. These results should be available in the native language of the group. As described in the literature, the information must be available “in physically, culturally, and linguistically accessible ways.”^{24(p97)}

Hearing researchers may partner with Deaf researchers, who have their own unique self-examinations to make within this epistemology, which include checking for bias in class or social differences, awareness of multiple identities and/or intersectionalities that Deaf participants may have, or how being an ingroup member may impact the perception of confidentiality among participants.¹⁴ Regarding the potential social differences observed in one study, Deaf participants referred to the Deaf group facilitators as “clever Deaf” and themselves as “ordinary Deaf”.⁶⁰ This is a recognition of the language acquisition and fluency differences between those who are raised in Deaf families compared to Deaf persons raised in non-signing homes or schools and may have the effect that this social difference can “increase awareness amongst both researcher and participant of the social divisions that exist between them.”^{36(p1)}

Methods

Autoethnographic Research Rationale and Methods

Within a critical framework, the methodology for this article was autoethnography, as the two authors engaged in ongoing reflection of the process of developing a research method that would honor a Deaf epistemology. The specific form of autoethnography chosen was analytic autoethnography, given a focus on

understanding a specific phenomenon from the researchers' etic view within a historical context and that of a Deaf-positive research methodology.⁸⁸

Autoethnography is the act of reflection on a lived experience⁴⁴ and falls within constructivist-interpretivist or critical-ideological paradigms.⁸⁹ In relation to this study, the purpose was to conceptualize a different epistemology and research process for the authors, presented as a narrative of the design and data analysis of a mixed-methods survey. Such an approach was chosen as it examines three aspects of the research as described in the literature, the process, culture and the self and draws upon a personal frame to explore issues of culture.⁴⁴ Such an approach requires "ethnographic empathy" something that only comes with introspection and experience in the community.⁴⁴ It signals a resistance to a positivist approach in research, in which the researcher is believed to be objective and removed from the community under study and the assumption is an objective truth that can be represented in writing.⁸⁹

There are several benefits to performing autoethnography. As an act of critical reflection, it can be used to develop a more critical consciousness.⁸⁹ It can lead to self-emancipation of the authors in their ability to give voice to their perspectives.⁸⁸ There is an ease to data collection and potentially richer insights. Overall, the goal of autoethnography is "the production of research in which person, phenomenon, and theory are articulated."⁸⁹ To that end, the intent is to lead to reader reflection and potentially improved conditions,⁸⁸ in this case in the quality of research methods. Richardson listed five outcomes of ethnography in general that should be considered, which included a "substantive contribution" to the canon, an "aesthetic merit" in that it stimulates thinking and dialogue instead of shutting it down, demonstrated "reflexivity" by the authors where

there is evidence of ethical reflection on subjectivity, a significant “impact” on the researchers, and findings that “express a reality” that rings true to others.⁵⁰

There are criticisms that have been made of an autoethnographic approach to research. Those critical of it have described it as “self-indulgent, narcissistic, introspective and individualized.”⁸⁸ Authors have questioned if the goal of the process was therapeutic for the writers or truly analytic.⁸⁹ It can also evoke a negative response in the reader and requires the authors to make themselves vulnerable by acknowledging their biases and limitations as well as understandings.⁸⁸

Nevertheless, autoethnography is being adopted by a growing body of researchers,^{45,88,89} and has been utilized in research conducted by or for Deaf people. In an early autoethnographic account of his experience of being Deaf in a hearing world, Humphries coined the word audism, denoting the belief in the superiority of the spoken word and the ability to hear versus the inferiority of someone who was Deaf and who made use of a visual, signed language.⁹⁰ One author (of three) provided autoethnographic detail to an exploration of narratives centered on communication barriers and access in the context of healthcare for Deaf patients, though not labelled as such.⁹¹ And, in an unjust but necessary compromise, personal narrative was offered as autoethnographic evidence of the lived experience of discrimination; a creative method enabling documentation of the knowledge held by Deaf people in their unwritten language that exists outside the bounds of inequitable citation formatting.⁹²

For this study, and as described in the literature, the authors were the object of the study.⁸⁹ Autoethnographic research can be written in first or third person or in the case of this study, a mixed approach where the findings will be written in first person.⁸⁸

For the purpose of this research, the unit of study included research notes, email exchanges and conversations between the two principal investigators (PIs).

Situating the researchers

When hearing researchers present findings from a research study with, about, or for Deaf communities, it is incumbent upon them to situate themselves in terms of their relationship to the Deaf community.¹⁶

At the age of 19, the first author (ES) began to learn ASL conversationally from Deaf friends. These same friends suggested she apply to Gallaudet University, which, at the time, admitted a few students that could hear in the undergraduate program as degree-seeking students. She spent the next five years either living on-campus at Gallaudet or off-campus with Deaf roommates while completing her degrees. She began interpreting at the request of a friend while at Gallaudet and has been a nationally-certified interpreter for 28 years at the time of writing this account. She was married to a Deaf man for over 10 years, the father of her three children. Her youngest son experiences Deaf gain⁹³ and has an affiliation with the Deaf community, and her oldest son identifies as a child of a Deaf adult (Coda).⁹⁴ She has extended family members who are Deaf and has worked closely with Deaf colleagues at every point in her career. She situates herself as an external-insider, as defined in another study.⁹⁵

ES was also the PI for the mixed-methods survey, and has an ongoing affiliation with the local Deaf community, including a social and professional relationship with the executive director of the Idaho Council for the Deaf and Hard of Hearing (CDHH). The Idaho CDHH executive director and ES had spoken about their mutual desire for a collaborative relationship between Idaho CDHH and the Idaho State University (ISU)

sign language interpreting program on matters of importance to the Deaf community and had both expressed the belief that we should seek projects that enhanced the relationship between the Deaf community and the organizations, even if the research area was less familiar—the essential component being the opportunity to foster full participation in an equitable process to address barriers faced by the community.

The second author (CM) began learning ASL as a second language in the mid 1980s and spent three years working as an interpreter with DeafBlind individuals and then 35 plus years as an interpreter to the Deaf community more broadly. He attended Gallaudet University as well to study school psychology where he began to question the validity of standardized tests when translated from English in ASL, with their inherent epistemology based on the majority culture. He went on to become nationally-certified as a sign language interpreter. Throughout his career, he has worked closely with Deaf peers and colleagues in post-secondary settings. He has studied and applied qualitative methodologies in various projects. He situates himself as an outsider to Deaf culture and when not interpreting also as an ally and advocate for Deaf rights.

Focus of the autoethnography

The focus of the autoethnography was an examination of the design and later analysis of a mixed method survey which examined the communication experiences of Deaf people in healthcare settings, with a focus on the provision of sign language interpreting services. This study involved an online survey that was created in both English and ASL with feedback from a focus group. Survey participants were given the option of responding to questions in either or both English and ASL, where they were video-recorded if they chose ASL using the LivingLens interface.

In large part, the data analysis and coding described in Anderson, et al.,¹⁴ was adopted, which provided a process for analyzing and coding qualitative data in ASL. The authors recommended no translation of the ASL into English and the inclusion of Deaf and hearing team members when determining codes.

There were a number of Deaf individuals involved in the creation and analysis of the data collected. All identified as native ASL signers and as culturally Deaf. They included three ASL models, four focus group members, five beta testers for the survey, two certified Deaf interpreters (CDIs), a Deaf consultant, and two Deaf analysts. In total, 15 Deaf individuals with some overlapping role definitions and four hearing individuals were involved in the design and analysis of the survey study, two of whom are fluent users of ASL. Individuals from these groups who worked with the data completed human subjects training, and the survey was approved by the Idaho State University IRB (IRB-FY2017-295). The impact each had on the process will be outlined next.

Application of Qualitative Data Analysis Method

Focus Group

The focus group members consisted of four individuals—two men and two women. When presented with a series of draft questions for inclusion in survey, the group suggested the addition of the following open-ended question: “Have you ever gone to an appointment when the healthcare professional said there would be an interpreter provided but when you went, there wasn’t an interpreter there?”

If respondents indicated that they did not use professional interpreters when communicating with health professionals, they were then asked, “Before, you said that

you didn't primarily communicate with your healthcare professional by using an ASL interpreter. Why?" The focus group selected the examples following and the order in which they appear. The extra-linguistic knowledge of Deaf culture⁹⁶ possessed by focus group members allowed them to select examples that would be useful to elicit spontaneous answers from survey respondents, but would not be "leading" in the sense that respondents would simply choose items from the examples and not add their own. Respondents gave reasons both in written English and in ASL that diverged greatly from the examples, which was the intended effect.

"Some examples of why people wouldn't communicate by using an interpreter could be:

- I prefer to go alone or write
- I don't feel comfortable with an interpreter or don't trust interpreters
- It's too difficult to get an interpreter or I don't know how
- Health professional refuses to get an interpreter or I don't want to pay for the interpreter myself"

Focus group members also suggested the items included in the rank ordering task used to indicate criteria that Deaf patients considered when selecting a new healthcare professional. Survey respondents could also add their own criteria and include it in the ranking. Most notably, focus group members included the selection "will provide professional interpreters" as an available selection criterion.

ASL Models

As suggested in the literature,⁷⁵ more than one ASL model was available to select from when respondents took the survey. The two ASL interpreters were members of different demographic groups in order to allow respondents to select a model they best understood. The Deaf content expert/interpreter, who is a white male, served as one of the ASL models, and the other ASL model was a Deaf Asian female from California.

Using two ASL models resulted in two different versions of the survey available for administration.

The ASL models met via videoconference and determined the procedure that they would follow in order to ensure consistency in presentation of the survey items. The researcher and ASL models also met to discuss the presentation and translation of the survey items. The translation of survey items that were first selected in ASL were then translated to English by the researcher and appeared below the video of each ASL survey item. After both models had filmed the survey items, the researcher and the ASL models reviewed the questions prior to acceptance.

Beta testers

Five Deaf beta testers were recruited by the Deaf consultant for survey testing. Versions of the survey had one of two ASL models and were either formatted for administration on a desktop computer or mobile device. Each beta tester took the survey at least four times to ensure that each version of the survey would be tested. Beta testers received written and ASL instructions in order to ensure consistency in the testing method. They were directed to answer the survey differently each time to ensure that that each survey path performed correctly. The researcher reviewed the recordings that were made by beta testers in order to troubleshoot video submission concerns or to refine the instructions. Two of the beta testers also reviewed the survey items and gave feedback on the clarity of the questions in order to improve the validity of the survey items.

Certified Deaf Interpreters (CDIs)

One of the ASL models, one of the coding team members, and the re-enactment model all had CDI training, and two were certified. Those that provided the re-enactment

of the sample quotes viewed the original narrative provided by survey respondents, and re-created the utterance. Within ASL/English interpreting parlance, this is often referred to as “shadowing” and is an intra-lingual rendering of an utterance that retains all aspects of the original utterance. Although we were unaware of it when we first employed re-enacted ASL exemplar quotes during an interpreted research presentation given in ASL in June of 2018, subsequently this has been reported in another scholarly publication, although without a spoken English translation provided.⁹⁷ Focus group participants in Singleton (supplemental) suggested the use of a “Deaf actor” when considering presentation of video examples.⁹⁸

Deaf Analysts

Two Deaf analysts were employed in the coding process. They worked individually with the PI and then individually to perform the preliminary coding. Then as a group, the two analysts and two researchers met to review the codes and to reach agreement on coding through discussion.

Findings of the Autoethnography

The results of the survey study will be detailed in a forthcoming publication. Some authors have called for the codification of researchers’ beliefs and practices into a terms of reference.^{16(p115)} Careful attention was given to these terms of reference (paraphrased in headings), and explain how the terms were applied to the research:

Resting the authority on the construction of meaning with community members¹⁶
by refraining from providing specific direction on details of the ASL translation

Although input from the PI was, at times, requested by the ASL models, she deferred to their extra-linguistic knowledge in details of the ASL translation. She

encouraged them to discuss the different audiences that they imagined would be viewing the survey, and tailor their interpretation to the audience that they believed would most benefit from their specific translation style, and has been employed by Deaf interpreters in other publications.⁹⁹

Acknowledgement that community members had the right to those things that they value to be fully considered¹⁶ by ensuring responses could be received in ASL and video introduction of the PI

Although it was a time-consuming challenge, ensuring that our survey could anonymously collect responses to open-ended questions in the native language of the respondents, ASL, had one of the most significant impacts. The survey, as required by the IRB, was conducted on the Qualtrics platform. We located a vendor, LivingLens,¹⁰⁰ that had a “plug-in” or API that allowed for collection of video responses. Without including the narrative responses, the data would not have been as rich.

The Deaf consultant and one CDI suggested that the PI provide a video introduction of herself at the beginning of the survey. They believed that this would increase trust in respondents, because they could personally evaluate the PIs sign language fluency, which is used as a measure of community involvement. They also suggested elements of the introduction that were essential including that the PI had Deaf family members and that she learned ASL from Deaf friends as opposed to taking courses.

Honoring ASL¹⁶ by the creation of a bilingual codebook (see <https://sites.google.com/isu.edu/qualitativecoding-asl-survey/home>)

Surveys could be answered in written English or in ASL. When determining the codes to apply to the qualitative data, the authors first met to develop axial codes. The Deaf coding team members were unfamiliar with the process of coding qualitative data, and so the authors developed broad inductive codes and categories to be presented to the Deaf team members. The Deaf team members joined the process with an organizing framework already in place, and so their experience was more similar to a deductive coding approach at that point.

However, an integrated approach was taken when the whole team worked on the data by generating taxonomies and themes. If the data were first presented to the team in written English or the discussion of the data were in spoken English during the process of inductive coding by the authors, the codebook noted inclusion and exclusion criteria in English first. Codes generated during coding team meetings conducted in ASL include definitions on video in ASL.

Negotiation of how research processes would be appropriate and meet cultural imperative and social needs¹⁶

Provision of example quotes has been problematic in research with ASL users, as the identity of the participant is revealed as part of the data.¹⁰¹ In the survey study, we resolved this dilemma by providing re-enactments of the original responses by either the Certified Deaf Interpreter (CDI) who had served as one of the ASL survey models/content expert and or a Deaf individual who had taken CDI training who was recruited for this task.

In a similar vein, in the exemplar quotes which are featured in our manuscript detailing the survey results (manuscript in progress), both a spoken English translation and captions were provided. The Deaf coding team members expressed a preference that a spoken translation be included in order to engage audience members who can hear, as they regarded the inclusion of vocal pitch/tone to be essential in the portrayal of Deaf respondent's comments. A draft ASL-to-English translation was provided by the PI, which was then reviewed by the Deaf re-enactment model who provided edits to ensure that cultural meanings were accurately conveyed.

Reflexivity

CM: As researchers we had to be open to constantly asking ourselves if we were being critical of our own analysis and not overriding the insights of the Deaf raters. We had to be conscious of how our presence shaped their responses. We had to constantly seek their input and make overt assurances their ideas were valued. This meant considering who would lead discussions and who would be present. We often worried that when both of the hearing researchers were involved, the two Deaf analysts would defer to us. The authors decided that only one would be present during the coding meetings with the Deaf team members. This was done to ensure a Deaf majority was present during the coding process and that there was not excessive impact from the majority-culture status of the authors.

Allowing for Ample Time and Remaining Patient

CM: Overall the process is very time intensive and requires a commitment to involving Deaf people at every stage of the research. While the benefits outweigh the

challenges, non-native researchers must be ready to spend the time with the research team to develop rapport and to understand their contributions and insights.

Vantage Point

ES: When the coding team assigned labels to thought units, we (CM and ES) noticed that our first code reflected our experience as interpreters or hearing people, while the Deaf analysis applied labels that reflected their experience as Deaf people. Our interpretation of meaning was influenced by different vantage points.

In one response, a Deaf patient explained how she could not continue to work with an interpreter who had damaged the working relationship by participating in something that was a conflict of interest. The Deaf analysts applied code labels that reflected the anger of the Deaf patient, and we (CM and ES) initially applied code labels related to unethical interpreter behavior. Both labels could apply, but it was interesting to see how our viewpoint influenced our selection. Another example occurred when a Deaf respondent explained how clinic staff had failed to heed her recommendation for an onsite interpreter to be provided and were dismissive of her expertise. We (CM and ES) initially applied code labels related to patronizing behavior, because we were focused on the behavior of the clinic staff, and the Deaf analysis applied codes related to frustration.

Importance of Bilingual Researchers

ES: When reviewing the written English narrative responses to the survey questions, there were some responses that would not have made sense if all coding team members were not bilingual. One response detailed the Deaf patient's self-advocacy when explaining to healthcare providers that they are obligated to provide ASL interpreters. The exact phrase as it appeared in written English was, "I'm closing, it is the

law.” All team members immediately understood this to mean, “I won’t debate this with you further, it’s the law.”

The use of the words “I’m closing” is a written English rendering of an ASL idiom that can be roughly translated to mean, “case closed.” Hearing researchers who do not know ASL, or hearing researchers with limited ASL exposure and fluency likely would not understand the intended meaning of the phrase used. It requires bilingual fluency to make a correct interpretation.

Conclusion and Recommended Research Framework

As a summary of the empirical paradigm applied and suggestions we have made for the consideration of hearing researchers in Deaf communities, we offer a figure (See Figures A1 and A2) listing questions for researcher consideration. We believe answering these questions can lead to successful collaboration between Deaf and hearing researchers or to a reconsideration of the appropriateness of the topic or researcher. Questions were either synthesized from a variety of research on appropriate Deaf/hearing collaborations^{11,14,16,22,24,36,46,58,84,98,102–104} or added based on our experiences as researchers in Deaf communities. Thoughtful consideration of the issues can ensure that research resulting from a Deaf/hearing research collaboration is trustworthy and accurate.

<p style="text-align: center;">Hearing Researchers: Questions to ask when considering conducting research with, about, or for Deaf communities</p> <p style="text-align: center;">Application of a transformative paradigm - Page 1 of 2</p>	
<p>Axiological Considerations</p> <p>Is this research a natural outgrowth of an ongoing relationship I have with members of the Deaf community?</p> <p>Is it appropriate for a person who can hear to conduct this research?</p> <p>Have I given a Deaf researcher the opportunity and support they need to take a leadership role? If not now, will I do so in the future?</p> <p>Am I familiar with the cultural norms and values of the Deaf community?</p> <p>Have I sought to further the human rights of and social justice for Deaf people through this research?</p> <p>Is the compensation provided to Deaf research subjects sufficient and an amount that is respectful of their contribution and expertise?</p> <p>Did Deaf people have input into the formulation of the research question?</p> <p>Have I accurately and comprehensively reported the qualifications of experts and interpreters that have participated in this research?</p> <p>Have I provided a positionality statement about myself and other researchers in this project?</p> <p>Have I been transparent with the community regarding how this research may benefit me personally?</p> <p>Have I informed subjects who will be reviewing their responses?</p>	<p>Ontological Considerations</p> <p>As a hearing researcher, do I have an understanding of the concept of "hearing privilege" and the impact it may have on research?</p> <p>Have I considered the impact of a pathological view of Deaf people, the history of eugenics use and other biomedical research abuse intended to prevent the growth of the Deaf community, and the fear healthcare research may trigger in participants?</p> <p>Have I considered the influence of power differentials in the relationship between research participants, research associates, and me?</p> <p>Do I recognize the inequality in communication, outcomes, and access that Deaf people often experience in healthcare settings?</p> <p>Am I aware of the need to engage with a variety of Deaf individuals and that one Deaf person's experience does not represent the entire community?</p> <p>Have I considered common formative experiences and identities of Deaf people and included representation of Deaf people who:</p> <ul style="list-style-type: none"> • Live in rural and urban areas • Are an ethnic minority • Have disabilities • Have experienced language deprivation • Vary in socioeconomic status • Socialize within the Deaf community • Choose not to socialize within the Deaf community • Are sexual or gender minorities

Figure A Page 1 of 2 Questions to Ask When Considering Research with Deaf Communities

<p>Hearing Researchers: Questions to ask when considering conducting research with, about, or for Deaf communities</p>	
<p>Application of a transformative paradigm - Page 2</p>	
<p>Epistemological Considerations</p> <p>Have I allowed the construction of meaning and knowledge in this research project to be determined by members of the Deaf community?</p> <p>Will my research increase knowledge about and help lessen prejudices against Deaf people?</p> <p>Have I regarded myself as a guest in the Deaf community and considered if my research may be detrimental?</p> <p>Have Deaf gatekeepers and organizations been enlisted early in the research process and compensated for their assistance?</p> <p>Are the goals and outcomes of this research driven by needs identified by members of the Deaf community?</p> <p>Have Deaf researchers either created or given input on the data analysis and interpretation process?</p> <p>Have I protected the identities of the research participants and considered the "small world" nature of the Deaf community?</p> <p>Am I fully aware of the impact translation and interpretation can have on the construction of knowledge, data collection, and the interpretation of meaning?</p> <p>Will research presentations include Deaf presenters to ensure audience knowledge increases with this experience and perspective?</p>	<p>Methodological Considerations</p> <p>Have I sought to ensure that there is a critical mass of Deaf people involved in all stages of the research process?</p> <p>Is the research environment "ASL friendly"? Is sign language visible in the environment and is ASL used for electronic and telephonic communication?</p> <p>Do the ASL models selected for the research materials and test instruments display diverse characteristics in terms of race, gender, sexual minority, visible disabilities, use of assistive listening technology, sign language proficiency, etc.?</p> <p>Have I allowed research participants to select the ASL model they best understand?</p> <p>Are recruitment, informed consent, and follow up processes culturally and linguistically accessible in ASL and written English?</p> <p>Have I allowed participants to respond to open-ended questions in ASL and not provided only limited choices due to the modality for data collection needed?</p> <p>Before the research is started, have I made a plan with Deaf gatekeepers and organizations regarding their ability to access, archive, or distribute the data and research results?</p> <p>Do I have a specific dissemination plan that will give community members open access (in the format they prefer) to the results in ASL?</p> <p>Has the ASL data collected been analyzed and interpreted without translation into English or has translation been delayed as long as possible?</p>

Figure B Page 2 of 2 Questions to Ask When Considering Research with Deaf Communities

CHAPTER THREE: “I’M TREATED LIKE I’M SUB-HUMAN”: A SURVEY OF
DEAF PATIENTS’ NEEDS FOR COMMUNICATION IN HEALTHCARE

Abstract

Objective

To describe the access and barriers to care and communication reported by Deaf users of American Sign Language (ASL) in healthcare settings.

Study setting

Primary data were collected from a nationwide online survey between June 2018 and January 2019.

Study design

Cross-sectional survey design presented in English and ASL to a convenience sample. Demographic, identity, health-care access, accommodation- and communication-, and interpreter- related variables were measured. Factors associated with foregoing care, using ad hoc interpreters, and satisfaction with medical care were determined using multivariate logistic regression. Qualitative variables measured reasons for not using ASL interpreters at appointments, foregoing care, and other experiences related to acquiring interpreters.

Data collection

Inclusion criteria of: Deaf adults in the US that indicated ASL was their primary mode of communication.

Principal findings

The majority (55.9%) of respondents indicate foregoing needed care and more than one-third were dissatisfied with their medical care (36.0%); Being younger, female (AOR 2.964 $p=0.094$), understanding less of the patient-provider communication and reporting more difficulty acquiring interpreter were associated with higher dissatisfaction with medical care.

More than 70% of respondents consider provision of interpreters a top consideration when selecting providers and consistently request interpreters when scheduling care, however, frequently interpreters are promised but not provided at their appointment and one-third indicate difficulty getting an interpreter for appointments.

Many report using ad hoc interpretation as their primary mode of communicating with providers (41.9%), those that consistently request interpreters (AOR 0.070 $p<0.001$), report less difficulty acquiring interpreters (AOR 0.312, $p=0.047$), and those that report understanding more of their communication with their provider (AOR 0.190, $p=0.003$) were less likely to use ad hoc interpreters.

Other than reports of mitigation strategies employed, qualitative responses were overwhelmingly negative and included themes of unmet needs and expectations for communication, inequity in care, and mitigation strategies employed by Deaf patients.

Conclusions

While not the experience of survey respondents, professional medically-trained sign language interpretation should be provided in healthcare settings for Deaf patients if a language-concordant provider is not available. Deaf patients report foregoing care,

barriers to communication and employ a variety of mitigation strategies when attempting to access care.

Introduction

The Department of Health and Human Services recommends that patients seek out providers that “listen to your opinions and concerns, encourage you to ask questions, and explains things in a way you understand”¹⁰⁵, underscoring the importance of effective two-way communication as an essential element of access to healthcare.²⁶ For the estimated 500,000 or more¹¹ Deaf users of American Sign Language (ASL), meaningful communication during healthcare encounters must be facilitated with either a language-concordant provider, the availability of which is limited,¹⁰⁶ or with the addition of services from a qualified sign language interpreter.³ Ineffective communication during healthcare encounters has significant negative impact on health outcomes, health literacy, and effectiveness of care for Deaf, DeafBlind, and hard-of-hearing persons who use ASL as their primary mode of communication (hereafter Deaf).²¹ Because of communication challenges in healthcare settings, Deaf adults have reported fear of healthcare encounters¹⁰⁷ and that they forego care,¹⁰⁶ including preventative services.⁹

The majority of Deaf patients would prefer to communicate in sign language during their healthcare appointments.⁷ Deaf patients comprise a unique segment of the limited English proficiency (LEP) patient population,¹⁰⁸ and studies regarding the quality of care provided for LEP patients have confirmed that when professional interpreters are provided, improved clinical outcomes, increased satisfaction with communication, increased comprehension, and decreased errors in communication result in care that either approaches or equals care received by patients without language barriers.¹⁰⁹

Interpreters with training and expertise in healthcare settings can empower Deaf patients to actively participate in their care and allow providers to mitigate gaps in health literacy.¹¹⁰

The impact of these improvements to care quality and health outcomes can, however, be diminished or enhanced by the accuracy and quality of the interpretation provided. The healthcare setting has been generally recognized as an environment that demands high levels of interpretation skill,¹¹¹ and, specifically, specialized sign language interpretation skills.¹¹² Interpreters who have received professional training commit fewer errors and the errors that they do commit are of lower potential negative clinical consequences than untrained (ad hoc) interpreters.¹¹³ In fact, there may be fewer misunderstandings and errors when there is no interpreter present than when the services of an ad hoc interpreter are provided.¹¹³

Deaf patients, patients with disabilities, and patients having LEP are at an increased risk of medical errors and adverse events.¹¹⁴ Deaf patients have ranked healthcare as the most important setting to have interpretation services, yet it is also the setting where they report the most difficulty obtaining services.¹¹⁵

Federal laws have been enacted which address the requirement for equal communication access for Deaf patients in healthcare settings, including the Americans with Disabilities Act (ADA) and subsequent updates. Entities that serve the public must provide communication access for Deaf patients that is as effective as communication experienced by patients who can hear.³ Despite the presence of these mandates for more than 30 years, complaints of ineffective communication continue to be received by

federal enforcement agencies,¹¹⁶ healthcare accrediting bodies,¹¹⁷ and state agencies serving Deaf people.⁴

Research confirms health disparities, poor health outcomes, and the resulting negative impact on health-related quality of life are experienced by Deaf individuals¹¹⁸, yet there is insufficient data gathered by public health surveillance, as a variety of barriers to participation exist that prevent Deaf people from reporting their specific communication experiences and levels of satisfaction with care.^{14,75} In a variety of studies, Deaf patients have reported significant difficulties in communication in healthcare settings^{8,107,119–123}, but, to date, there has been no quantification of the types, frequency, and severity of communication barriers and the impact on access to care. Data regarding preferences for interpreter provision during healthcare encounters have been reported from the U.K. and Greece, but no such information is available on the preferences of the population of Deaf people in the United States.^{8,119,124,125}

We sought to investigate relationships between communication modes and techniques employed during healthcare encounters, preferences for provision of interpreting services, reported experiences of discrimination and respondent's self-identification of affiliation with Deaf culture, reported successful comprehension during encounters, and demographic characteristics. We hypothesized that Deaf patients preferred the services of professional interpreters during healthcare encounters and that they engaged in a variety of self-advocacy techniques to promote the availability of those services. We further hypothesized that there was a relationship between foregoing care and communication barriers.

Methods

The present study examines a bilingual (ASL and English) self-administered online survey using mixed-method design completed by a convenience sample of Deaf users of ASL. Respondents were recruited through snowball sampling, requests from state directors of agencies for the Deaf, and an advertisement on an online daily ASL news program. Items presented on the survey included 19 forced response questions, one of which appeared on follow-up; seven questions that provided fixed responses and an optional narrative response in either written English or ASL; three open-ended questions which accepted only narrative responses, two of which appeared on follow-up; and a list that respondents could rank in order of importance with eight fixed choices and optional written English or ASL items respondents could create and include in the ranked items. The written English survey items are available in Appendix B and the ASL items are included in the supplemental materials, both licensed under a Creative Commons BY-NC 4.0 license.

Survey items were selected from standard health surveillance instruments or created based on insight gained from a retrospective study of complaints filed regarding communication in healthcare settings by Deaf patients,⁴ feedback from a focus group comprised of Deaf community members, and input from the Idaho Council for the Deaf and Hard of Hearing (CDHH). ASL survey items were initially composed and English items were translated by the principal investigator (PI), a certified medical interpreter, and a Certified Deaf Interpreter (CDI) with extensive translation experience. Back-translated or translated items in English were reviewed by a public health expert. The survey was administered using Qualtrics¹²⁶ with ASL video data collected from within

the same platform via a LivingLens¹⁰⁰ plug-in. Five Deaf individuals piloted the survey before distribution and feedback was incorporated in the final version. Based on best practices,¹⁰⁴ survey respondents could select from two ASL models, a white male or Asian female. Respondents were presented with a short story signed by the ASL models, and selected their preferred version. Informed consent was presented by the ASL model selected, and respondents confirmed their consent and that they were 18 or older. ASL versions were reviewed for consistency by the PI.

Respondents who confirmed that ASL was their primary mode of communication were entered in a drawing for one of twenty available Wal-Mart gift cards. Respondents who did not identify ASL as their primary mode of communication were excluded from the survey. If respondents indicated that they were DeafBlind, a screen-reader accessible message encouraged them to contact the PI for accommodations. The study was approved by the Idaho State University Human Subjects Committee.

Quantitative Methods

Measures

Demographic variables included age by age group, self-reported population density (urban vs rural), marital/partner status, sex, and education. Identity variables included how one identifies (Deaf, Hard of hearing, Late (D)deafened, or deaf), age of onset of deafness (since birth, before 3 years old, between 4 and 18, and 19 or after). Healthcare access-related variables focused on where regular care was received, whether or not respondents forego care when care was needed, frequency past visit, and whether or not having one's insurance accepted is the most important determinant when selecting a provider. Accommodation and communication related variables included how a

respondent primarily communicates at appointments, who typically schedules medical appointments, how much one understands their provider, and how much they perceive the provider understands them. Interpreter-related variables measured whether the provision of professional interpreters was the most important determinant when selecting a provider, if respondents ask friends for recommendations on which providers provide interpreters, how difficult it is to acquire an interpreter at appointments, how frequently interpreters are requested when making appointments, and among those who request interpreters, if interpreters are promised but ultimately not provided. Lastly, satisfaction with medical care was a health-outcome related variable.

Demographic and identity variables were cross tabulated with healthcare access, accommodation- and communication-, interpreter-, and satisfaction variables to summarize the data. Chi-square tests (and Fisher's exact tests when cell counts were less than five) were utilized to determine differences in demographic and identity related distributions according to healthcare access, accommodation- and communication-, interpreter-, and satisfaction variables with significance noted at alpha levels of 0.1, 0.05, and 0.01. Relationships between variables and select healthcare access (Foregoes care when care is needed), accommodation- and communication- (Uses Lipreading, writing, or ad hoc interpretation at appointment), and satisfaction (Those "Very satisfied" or "Satisfied" with medical care) variables of interest were reported using bivariate and multivariate logistic regression. Multivariate modeling was conducted using a forward stepwise method with an entry level and exit level of $\alpha=0.1$ and significance reported using p-values at $\alpha=0.1$, 0.05, and 0.01 levels. Analyses were conducted using Stata version 12 (StataCorp).

Qualitative Methods

A thematic analysis¹²⁷ was performed on narrative responses provided in written English (n=133) and in ASL (n=32). Combined, 45+ minutes of ASL narrative responses were received. Rigor was established through triangulation of the themes discovered in the narrative responses with the context provided by the quantitative data; consistency of themes with reports in other studies; and agreement by members of the coding team.¹²⁸ The coding team included the two Deaf research assistants, a certified sign language interpreter/researcher who can hear, and the PI, who is a certified sign language interpreter as well. The coding and analysis process followed an adapted linguistically and socio-politically method of inquiry¹⁴ to be detailed in a later publication.¹²⁹

The process of assigning codes and thought units (n=646) was iterative and constant-comparative.¹³⁰ Written English narrative responses were reviewed by two researchers who assigned preliminary *in vivo* codes to 22 broad themes, applying a grounded theory approach. Preliminary codes and definitions were presented to other team members in a draft codebook. The PI met individually with the two remaining team members to agree on the coding process, which was written down and shared with all team members.

Team members then individually reviewed, coded, and sorted all written responses into thought units. Parsing of thought units, codes applied, code labels and refinements to the codebook were agreed upon as a whole research team. Disagreements were resolved through team discussion. ASL narrative responses were viewed next and coded using GoReact,¹³¹ with team members individually reviewing, sorting and coding ASL responses individually. Codes were added in ASL and existing codes were refined

based on ASL narrative responses in the codebook. Finally, all responses, written and ASL, were re-coded using the completed codebook, with more than 90% agreement between team members in code categorization. The bilingual codebook is available in the supplemental materials and online at <https://sites.google.com/isu.edu/qualitativecoding-asl-survey/home>

Quantitative Results

Our sample of users of ASL (n=170) was normally distributed across age groups with the majority in the middle age groups (25 to 54 years of age – See Table 3.1). Participants were mostly from the urban areas (73.5%) and identified as female (63.6%). Nearly half of respondents were married or partnered (43.6%), and had graduated from college (53.5%). The majority identified as Deaf (77.9%) and reported onset of deafness since birth (63.3%).

In terms of health care access related variables, 10.1% report using the emergency room for regular care rather than clinics or other healthcare venues. The majority (55.9%) skipped care when care was needed. Approximately 14.6% of respondents did not visit a healthcare provider within the past year. Whether or not the provider accepts insurance was the most important determinant for selecting a healthcare provider for 40.7% of respondents.

Related to the accommodation- and communication-related variables, 85.4% of respondents scheduled their own medical appointments. Approximately 75.0% indicate that they understand “everything” or “almost everything” that their provider communicates. 70.9% of respondents report thinking that their provider understands “everything” or “almost everything” that they communicate. The majority (56.8%) report

that the primary mode of communication at their healthcare appointment was through a professional interpreter, followed by “Writing” (20.3%) and “Lip-reading” (15.5%) and having a family member interpret (6.1%).

In terms of interpreter-related variables, 24.0% indicated that the provision of a professional interpreter was the most important aspect when determining where to receive medical care with 76.7% indicating it was in their top three considerations when selecting providers. Approximately 45.4% had asked friends which healthcare professional(s) will provide interpreters when selecting a provider. Most (71%) report “Always” or “Often” requesting that the healthcare professional provide an interpreter at their appointment. Nearly 4 of 5 report that they ever had an interpreter promised but not provided at their appointment (79.5%). Of these, more than half indicated that this happened frequently (51.2%). One-third (33.6%) report difficulty (“Very difficult”/ “difficult”) obtaining an interpreter for medical appointments. Regarding who is perceived to pay for interpretation services among those that report using interpreters, 52.3% indicate that their health professional pays for the interpretation services followed by “unknown” (20.5%) and “the hospital” (17.1%), and “my insurance company” (6.8%).

Approximately 36.0% report being dissatisfied with their medical care.

Table 3.1 Demographic and identity according to healthcare access and appointment communication variables

Demographic and deaf-related questions	Healthcare access-related variables				Accommodation and communication-related variables			Interpreter-related variables				Satisfaction with medical care (n=45 of 125)*		
	Number (Overall n=170 %)	Regular care (% using Emergency Rooms) (n=15 of 149)	Forego care when care was needed (% Yes) (n=80 of 143)*	Recent visit (% no visit in past year) (n=23 of 157)	Accept insurance is the most important determinant (n=70 of 172)	Primary communication mode at appt. (professional interpreter) (n=83 of 146)*	Schedule appt. (% "meets" in 123)	Perceived amount of understanding by provider (n=105 of 148)	Amount of understanding by patient (n=111 of 148)	Provide professional interpreter (most important) (n=31 of 129)	Ask friends if interpreter provided (n=55 of 121)		Ever interpret promise; not provided (% Yes) (n=97 of 122)	Request interpreter? (n=88 of 124)
Age														
18-24	11 (6.5)	6.7	6.3	8.7	4.3	1.2	2.9	3.6	0	1.8	4.1	3.4	4.9	**
25-34	34 (20.0)	13.3	20.0	13.0	22.9	16.9	16.2	17.1	9.7	16.4	18.6	17.1	14.6	11.1
35-44	47 (27.7)	46.7	33.8	56.5	24.3	28.9	30.5	27.0	29.0	34.6	28.9	27.3	39.0	20.0
45-54	40 (23.4)	13.3	23.8	13.0	28.6	22.9	24.8	27.0	19.4	20.0	23.7	21.6	19.5	31.1
55-64	22 (12.9)	13.3	13.8	8.7	14.3	16.9	11.4	13.5	16.1	14.6	15.3	15.9	9.8	24.4
65 or more	16 (9.4)	6.7	2.5	0	5.7	13.3	14.3	11.7	25.8	12.7	9.3	14.8	12.2	11.1
Population Density														
Urban	122 (73.5)	73.3	75.0	69.6	74.3	71.1	74.3	73.9	71.0	80.0	74.2	72.7	73.2	73.3
Rural	44 (26.5)	26.7	25.0	30.4	25.7	28.9	25.7	26.1	29.0	20.0	25.8	27.3	26.8	26.7
Marital status														
Single	58 (35.2)	66.7	35.0	47.8	37.1	36.1	32.4	31.5	22.6	29.1	34.0	30.7	31.7	*
Married/partnered	72 (43.6)	6.7	42.5	39.1	47.1	51.8	51.4	51.4	48.4	50.9	49.5	53.4	36.6	42.2
Divorced/Widowed	24 (14.6)	13.3	13.8	8.7	11.4	9.6	13.3	13.5	25.8	12.7	12.4	12.5	22.0	33.3
Separated	5 (3.0)	6.7	3.8	0	0	0	0	0.9	3.2	1.8	1.0	1.1	4.9	15.6
Other	6 (3.6)	6.7	5.0	4.4	4.3	2.4	2.9	2.7	0	5.5	3.1	2.3	4.9	4.4
Sex (% female)					*									*
Female	105 (63.6)	80.0	72.5	56.5	68.6	62.7	62.9	66.7	58.1	70.9	68.0	64.8	73.2	80.0
Male	50 (30.3)	13.3	25.0	39.1	30.0	31.3	33.3	29.7	38.7	27.3	29.9	31.8	26.8	17.8
Other	10 (6.1)	6.7	2.5	4.4	1.4	6	3.8	3.6	3.2	1.8	2.1	3.4	0	2.2
Education					**									
Did not finish high school or GED	10 (6.1)	6.7	2.5	4.4	1.4	2.4	2.9	1.8	3.2	3.6	2.1	2.3	**	2.2
High school graduate or GED	29 (17.8)	26.7	17.5	26.1	22.9	18.1	18.1	17.1	16.1	12.7	16.5	17.1	12.2	20.0
Some college	37 (22.7)	33.3	22.5	21.7	15.7	15.7	18.1	18.0	32.3	23.6	23.7	19.3	39.0	28.9
College graduate	87 (53.4)	33.3	57.5	47.8	60.0	63.9	61.0	63.1	48.4	60.0	57.7	61.4	43.9	48.9
Identity														
Deaf	134 (77.9)	80.0	88.8	82.6	80.0	79.5	79.1	78.4	96.8	92.7	85.6	86.4	87.8	86.7
Hard of Hearing	15 (8.7)	6.7	5.0	13.0	11.4	12.1	9.5	9.9	0	1.8	6.2	5.7	7.3	4.4
Late (D)/deafened	2 (1.2)	0	1.3	0	1.4	1.2	1.0	0.9	0	0	1.0	1.1	0	2.2
deaf	12 (7.0)	13.3	5.0	4.4	7.1	7.2	10.5	10.8	3.2	5.5	7.2	6.8	4.9	6.7

When looking at differences in demographic according to healthcare access, accommodation and communication, interpreter, and satisfaction related variables (Table 3.1), we found significant differences in the age distribution of those that skipped care when care was needed ($p=0.015$), had no visits in the past year ($p=0.017$), scheduled their own appointments ($p=0.001$), reported understanding by the patient during healthcare visits ($p=0.016$), primarily used professional interpreters at appointments ($p=0.048$), rated professional interpretation services was the most important factor when selecting a provider ($p=0.028$), and were satisfied with medical care ($p=0.037$).

Those living in urban areas were more likely to schedule their own appointments ($p=0.042$). Those married/partnered reported proportionately greater understanding as a patient ($p=0.029$), perceived understanding by their provider during medical appointments ($p=0.098$), scheduled their appointments themselves ($p=0.092$), rated professional interpretation services was the most important factor when selecting a provider ($p=0.068$), and had less dissatisfaction with their medical care ($p=0.086$). Females were more likely to be dissatisfied with their medical care ($p=0.090$) and more likely to rank whether or not the provider accept their insurance was the most important factor when selecting a provider ($p=0.092$). Those that graduate college were proportionately more likely to schedule their own medical appointments ($p=0.001$), understand more of what their provider communicating during that appointment ($p=0.010$), and rank whether or not the provider accept their insurance was the most important factor when selecting a provider ($p=0.020$). Those with “some college” were proportionately more likely to report difficulty acquiring an interpreter (39% $p=0.037$).

There were no differences in the distribution of healthcare access, accommodation

and communication, interpreter, and satisfaction related variables according to how reports their identity as a Deaf person. There were differences in the distribution of onset of deafness according to reporting difficulty acquiring an interpreter ($p=0.077$).

Forego care when care was needed

After adjusting for age, having ever asked friends which healthcare professionals will provide interpreters, and satisfaction with medical care, those 65 or over were much less likely (AOR 0.018) to forego care when care was needed compared to those in the 18-24 age group (Table 3.2). Respondents that had ever asked friends which healthcare professionals would provide interpreters were 5.4 times more likely to have skipped care when care was needed compared to those that had not asked friends for recommendation. Those that were dissatisfied with their medical care were 3.7 times more likely to forego care when care was needed compared to those that were satisfied with care.

Primarily use ad hoc interpretation at healthcare appointments

After adjusting for requesting that the healthcare professional provide an interpreter, provider understanding me, experience getting an interpreter for medical visits, those that consistently request that the healthcare professional provide an interpreter were less likely to use ad hoc interpretation at healthcare appointments (AOR 0.070). Those that reported less difficulty acquiring interpreters for medical appointments were less likely to use ad hoc interpretation at healthcare appointments. Those that report understanding “Everything”/“Almost everything” of the communication with their provider were less likely to report primary communication at healthcare appointments using ad hoc interpretation compared to those that understood less of their communication with providers.

Dissatisfaction with medical care

After adjusting for age, sex, foregoing care, understanding provider, provider understanding me, and experience getting an interpreter for medical visits females were approximately 3 times more likely to be dissatisfied with medical care compared to males (AOR 2.967 p=0.096). Those who reported that they understand “Everything”/”Almost everything” of communication with their provider were less likely to be dissatisfied with medical care compared to those who understood less of their communication with their provider (AOR 0.111 p=0.001). Similarly, those who reported that their provider understands “Everything”/”Almost everything” of their communication were 74% less likely to be dissatisfied with medical care compared to those whose providers are perceived to understand them less (p=0.067). Those whose experience getting an interpreter for medical visits was rated “Easy”/”Very Easy” or “Neither difficult nor easy” were less likely to be dissatisfied with medical care (AOR 0.501 p=0.286 and AOR 0.173 p=0.016, respectively) compared to those whose experience getting an interpreter was “Very difficult”/”Difficult”.

Table 3.2 Demographic, healthcare access, accommodation and communication, and satisfaction factors associated with foregoing care, consistency requesting healthcare provision of interpreters, primary mode of communication at healthcare appointments, and satisfaction with medical care among users of ASL.

	Health care access-related variables		Accommodation and communication related variables		Satisfaction with Medical Care	
	OR	AOR	OR	AOR	OR	AOR
Demographic						
Age						
18-24 (Ref)	-	-	-	-	-	-
25-34	0.800	0.400	0.15*		8.333*	5.065
35-44	1.350	0.573	0.10**		7.500*	5.004
45-54	0.760	0.266	0.11*		7.727*	2.412
55-64	0.825	0.549	0.05*		13.000**	21.621*
65 or more	0.09**	0.018**	0.05**		65.000***	13.072
Sex (ref=Male)						
Female	1.88*	-			0.375**	0.337*
Other						
Health care access-related variables						
Regularly seeks healthcare using the Emergency Room (n=15 of 149)						
No recent healthcare visit in (past year) (Ref=had recent visit) (n=157)			4.18**		0.156***	-
Forego care when care was needed (ref=No)(n=143)*			2.67**			
Accommodation and communication related variables						
Primary communication mode at appt. (Ref=prof. interpreter)(n=146)						
ASL – Family member interprets					0.12***	-
Writing					0.32**	-
Lip-reading					0.26**	-

I understand "everything/Almost everything" of communication with provider (Ref=Sometimes, Very Little, None) (n=148)	0.35**	-	0.22***	0.19***	9.87***	8.974***
My provider understands "everything/Almost everything" of communication with me (Ref=Sometimes, Very Little, None)(n=148)	0.39**	-	0.11***		15.64***	3.744*
Ever asked friends which healthcare professionals will provide interpreters (Ref = do not ask)(n= 121)	4.37***	5.372***			0.387**	-
Interpreter frequently promised ("Always"/"Often"/"Sometimes") but not received (ref="never", "once", "rarely")	1.88*	-	1.88*		0.41**	-
"Always" or "often" Request that the healthcare professional provide an interpreter (Ref="do not"/"rarely"/"sometimes ask for interpreter")			0.10***	0.070*	2.02*	-
Experience getting an interpreter for medical visits (ref="Very difficult"/"Difficult")						
"Neither difficult nor easy"	0.44*	-	0.21***	0.13***	4.41***	1.996
"Easy"/"Very easy"	0.36**	-	0.24***	0.312**	9.52***	5.777**
Satisfaction with medical care						
"Very satisfied" or "Satisfied" with medical care (ref=Fair, Unhappy, Very unhappy)	0.268***	0.406*	0.249***		-	-

Only significant odds ratios are shown ***p=value<0.01 **<0.05 *<0.1

Qualitative Results

A nuanced picture of factors, personnel, emotions, and experiences emerged from the narrative responses provided by Deaf patients. These are expressed as an overarching theme of “Deaf patients’ unmet needs and expectations for communication in healthcare settings”. Respondents detailed empowered attempts and successes when ameliorating the negative impact of healthcare failures in communication as expressed in the sub-theme “Mitigation strategies”. Codes including an expression of frustration, either lexical or via facial grammar, were noted in the majority of responses when analyzing thought units categorized in the sub-theme “Inequity in care”. The tension between interpreter services as an assurance of effective communication and the potential harm and loss that can occur when ad hoc (untrained), unqualified, or unethical interpreters are provided is conceptualized in the sub-theme “Interpreters as a mixed blessing.” Themes, subthemes and properties are presented visually in Figure C, with the context of inequity in care including a visual representation of the pervasive frustration experienced.

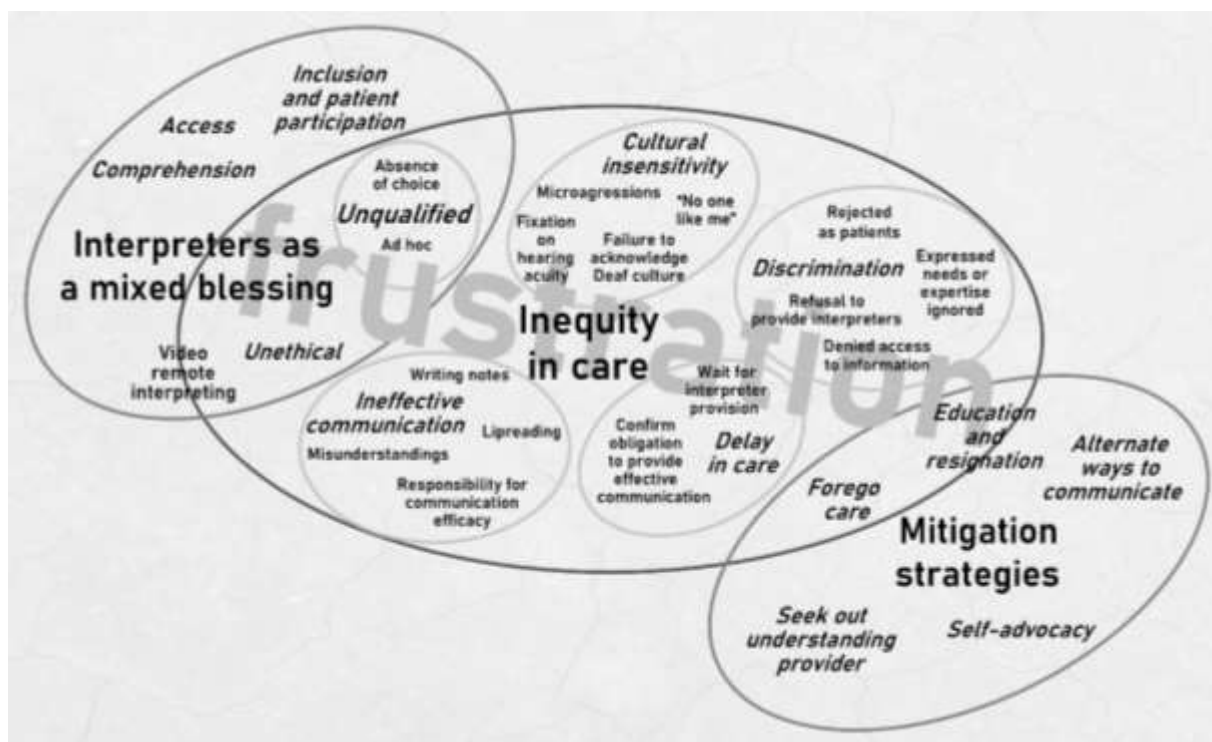


Figure C Deaf patients' unmet needs and expectations for communication in healthcare settings: Themes, sub-themes and properties

Theme: Inequity in care

Respondents overwhelmingly described failures to receive care that they perceived to be on par with the care received by patients who can hear. These inequities included behavior from healthcare system personnel which was culturally insensitive; delays in care that were not experienced by patients who can hear, communication which was ineffective during healthcare interactions, and overt discrimination against Deaf patients.

The provision of culturally competent care is the standard of care for healthcare interactions.²⁶ Respondents spoke of their inability to be themselves while receiving care, because the provider or staff did not understand or acknowledge that the patient was a member of the Deaf community and that this affiliation should be addressed when providing culturally competent care. ([Quote V.1 in English](#))



Video 1 Survey Quote V.1 in ASL

The healthcare system was described as being “not mine” but “theirs” and that there was no one “like me” during interactions in healthcare settings, especially providers. An outgrowth of care which was not culturally competent was what was described to be a “fixation” on the patient’s inability to hear as opposed to the reason that they had requested to be seen for care. ([Quote V.2 in English](#))



Video 2 Survey Quote V.2 in ASL

Respondents related instances in which re-direction required several attempts before being successful. Experiencing microaggressions was noted in relation to culturally insensitive behavior or remarks. ([Quote V.3 in English](#))



Video 3 Survey Quote V.3 in ASL

The burden for communication success was often placed on the Deaf patient during interactions, and, although patients reported employing a variety of strategies to ensure their comprehension, ineffective communication routinely occurred when the Deaf patient was unable to understand what the provider or staff people were attempting to communicate. Deaf patients spoke of the frustration experienced when attempting to understand but having to rely on methods other than sign language to receive information, such as lipreading or written notes. ([Quote V.4 in English](#))



Video 4 Survey Quote V.4 in ASL

Written notes were reported as ineffective, due to the lack of context and medical terminology used. Respondents reported the failure of providers to successfully address the lack of communication as a failure to meet their needs, and that some felt that there was no other option than to seek care from another provider after repeated requests for effective communication in order to participate in their own care. ([Quote V.5 in English](#))



Video 5 Survey Quote V.5 in ASL

Delays in care were most often reported with a request for interpreter services and either: waiting for an interpreter to be available, waiting for staff to confirm the legal obligation to provide sign language interpreter services, or delays as staff determined where and how to request interpreter services. ([Quote V.6 in English](#))

**Video 6****Survey Quote V.6 in ASL**

Respondents reported arriving at appointments only to have to wait longer than other patients because interpreter services were not requested in advance or having to return because confirmed services were not available at time of the appointment. Urgent care was mentioned as a treatment setting in which care was delayed due to the unavailable services, yet some providers would not allow the patient to be seen until an interpreter arrived, even when the patient was willing to do so. ([Quote V.7 in English](#))

**Video 7****Survey Quote V.7 in ASL**

Respondents also reported that the protracted communication process resulted in encounters lasting longer than necessary or longer than they would have if interpreter services had been provided.

Instances of overt discrimination included refusals on the part of healthcare entities or personnel to comply with federal law prohibiting discrimination when refusing to accept Deaf people as patients, denying interpreter services when requested and necessary for even the most basic of communication ([Quote V.8 in English](#)),

**Video 8****Survey Quote V.8 in ASL**

failure to include the Deaf patient in their own care, and refusal to recognize the expressed needs of the Deaf patient, even when the patient is experienced in the provision of accommodations and aware of which accommodations are ineffective or successful.

[\(Quote V.9 in English\)](#)

**Video 9****Survey Quote V.9 in ASL**

One patient remarked, “If I ask for an interpreter, sometimes the place I’m going won’t see me.”

Theme: Mitigation strategies

An array of strategies employed by respondents was reported when making attempts to ensure equitable and successful care. Positive strategies included self-advocacy, personally proposing or providing alternative ways to communicate, educating staff and providers regarding the need for communication, and intentionally seeking out providers known to be patient and understanding in their approach to care of Deaf patients. ([Quote V.10 in English](#))



Video 10

Survey Quote V.10 in ASL

Negative strategies included resignation after repeated education attempts and foregoing care. ([Quote V.11 in English](#))

**Video 11****Survey Quote V.11 in ASL**

Some respondents described their success in receiving sign language interpreter services after informing the provider or clinic of their obligation to comply with the Americans with Disabilities Act mandate to provide effective communication. “I’ve had a few private practice medical professionals that apparently had no idea how to get an interpreter or the ADA law regarding interpreters. So, I’ve had to explain to them how it works and who pays.”

Less than a third of respondents reported that they would employ alternative means of communication, using their lifetime of experience as a Deaf person to decide when that was appropriate. Writing, lipreading, and typing on a computer were mentioned as some strategies used successfully in some situations. Some respondents indicated they were strategic about which communication mode was best suited for the situation when they knew what to expect. “I rarely request an interpreter for dental or

vision appointments, as those are pretty cut and dry.” Some respondents described experiences in which the provider was proactive about communication and, in the absence of an interpreter, regularly checked for understanding on the part of the patient, which was an acceptable alternative ([Quote V.12 English](#))



Video 12 **Survey Quote V.12 in ASL**

Sadly, resignation and the decision to forego care were also reported as mitigation strategies. Respondents explained how they simply decided to “give up” on understanding during appointments or simply not seeking care unless the situation was dire. ([Quote V.13 in English](#))



Video 13 Survey Quote V.13 in ASL

Theme: Interpreters as a mixed blessing

Consistent with the data from the quantitative analysis, respondents reported a preference interpreting services be provided for healthcare encounters. “I like to know that a healthcare provider will get interpreters, and do that right away.” Deaf patients highlighted the importance of communication comprehension. “I’d rather use an interpreter when I have a doctor’s appointment because of the very important information and need to improve my health.” Having an interpreter was noted by some as a way to access information that requires health literacy. “I like to have the interpreter read through the written information like medication notes and visit summaries with me.”

Interpreters could also become a barrier to care. Respondents reported negative experiences with interpreters, interpreters who were not qualified or interpreters that behaved unethically. “Interpreters should not accept medical assignments they are not

skilled and qualified for...They aren't knowledgeable about medical terms or concepts.”

The emotional labor of convincing healthcare entities to provide an interpreter sometimes outweighed the benefit. Many respondents related experiences with under- or unqualified interpreters who were unable to accurately convey the message. “Interpreters are a hassle. Sometimes I get an interpreter that is not ‘qualified’ to work at hospitals. I prefer writing to avoid confusion.” Patients generally reported video remote interpreting (VRI) as ineffective and unsuccessful for the provision of interpreting services.

Typically, [the] health care professional hires subpar interpreters who are clearly unqualified to interpret in medical settings and who have horrible receptive skills. [*“Receptive skills” describe the task of interpreting from ASL into spoken English.*] Furthermore, the subpar interpreters often assume deaf clients to be low-functioning with a lack of academic education and proceed to interpret everything in extremely simple words, causing confusion. You get what you pay for – when getting interpreters at very cheap rates.

The policies and procedures of the healthcare entity were, at times, the cause of the inability to receive interpreter services. Contractual obligations to unqualified or unethical interpreting service providers were valued over patient needs. ([Quote V.14 in English](#))



Video 14 Survey Quote V.14 in ASL

Cost-cutting by providing VRI was another example of policies and procedures that were honored over patient needs.

Another aspect which illustrates the tension of wanting interpreting services yet not was the experience of discomfort and loss of privacy with an interpreter. Respondents cited the close-knit nature of the Deaf community, generally agreed to have less than three degrees of separation between members, and reported behaviors from interpreters that would be in violation of the ethical codes of interpreters, although it may not be possible to pursue a remedy for this behavior, as interpreting is a wholly unregulated profession in more than one-third of the states.

“...the interpreter was very unprofessional. I was put under anesthesia [for a delivery by C-section]. I woke up to find the interpreter going on and on about how she asked the doctor to watch my C section because she had

experienced one and wanted to see it. A very special moment was darkened by this violation of my rights.”

Some respondents clearly expressed a desire to not have interpreter services for this reason: “Interpreters are not to be trusted. Do not bring one.”

VRI was reported as being unsuccessful and undesirable in most cases, but was often the only communication option offered. Some patients struggled because of the difficulty of understanding a language that uses three dimensions but presented in only two dimensions on a computer screen. “Some of my private doctors will not provide the [interpreter] service or only offer VRI which is difficult for me to follow due to the one missing dimension and my age/vision.” Other respondents indicated it was acceptable in certain situations: “I’m okay with VRI for daily and routine appointments, but am VERY concerned about using VRI for more serious and complicated medical issues.” Clarity of transmission, insufficient staff training, and environments where VRI could not be provided due to conflicting equipment (e.g. radiation therapy/MRI) were cited as the most common problems.

Discussion

Summary of Key Results

This nationwide cross-sectional survey of Deaf patients represents the first study focused on effective communication in healthcare settings. More than half of Deaf patients reported foregoing care when care was needed (55.6%) and in narrative responses, indicated that because healthcare entities refused to provide interpreter services, provided unqualified interpreter services, or the “fight” to convince them to provide interpreting services was exhausting, they did not seek care. Provision of

interpreter services was ranked as one of the most important factors considered by Deaf patients, and they asked their friends which clinic or facility would provide those services when selecting a provider. And, despite the risk of receiving a subpar interpreter, Deaf patients who received professional interpreter services were more satisfied with their care and reported that they understood their provider and their provider understood them more successfully than those patients who received either ad hoc interpreter services or no interpreter services.

Experiences recounted in narrative responses included a considerable number of situations where care was severely compromised either because of no interpreter services or unqualified interpreter services. Deaf patients reported patently unethical behavior on the part of some “interpreters”, although it is not known if those interpreters were certified or licensed. Respondents often reported a complete absence of choice in the accommodations they were given, despite having more experience with receiving accommodations than those providing them. When they suggested alternatives to the accommodations offered based on knowledge, they reported being turned down. They often receive interpreting services in a format that provides ineffective interpretation, VRI, because staff lack proper training to set up the equipment or the picture is not clear enough to see the interpretation.

Legal Obligations and Dilemmas Regarding Interpreter Services

Clinics and healthcare facilities are prohibited from charging or requiring reimbursement for Deaf patients for interpreter services.¹³² ADA allows the covered entity to select the accommodation they will provide. This means that Deaf people often do not select the interpreter provided,⁹² and the covered entity is not required to consult

with the patient before making such a selection.¹³³ Of the 50 states and the District of Columbia, only 28 states require that interpreter be licensed, registered, or certified by the state in order to provide interpreting services.¹³⁴ Of the states that do regulate the provision of interpreting services, only one requires additional training or an endorsement to provide interpreting services in healthcare environments.¹³⁵

Once secured, interpreters can be problematic as an accommodation.¹³⁶ If the interpreter is unqualified or behaves unethically, the Deaf patient may face the prospect of the additional emotional labor when deciding to inform the provider of the insufficient interpretation (and risk seeming ungrateful), file a complaint, or discuss the ineffective interpretation with the interpreter.¹³⁷ None of these choices is without complication. If the patient decides to file a complaint regarding the provision of an unqualified interpreter, the patient must determine which entity has enforcement authority, selecting from The Joint Commission, their state board of health, state board of interpreter licensing (if interpreting is regulated in their state), state office of civil rights, the Department of Justice ADA division, or the HHS Office of Civil Rights, among others. All complaint filing processes are available in English and although many provide instructions in Spanish or other spoken languages, few to none provide ASL instructions.

Deaf patients can file lawsuit in federal court against the provider, but, in addition to retaining an attorney to represent them (who may or may not be willing to provide an interpreter for the consultation), the Deaf patient must have “standing” to file the lawsuit against a provider. This means that they must be a current patient of that provider and, despite the lack of communication, may not be receiving care from another provider or the suit will be dismissed.¹³⁸ Clearly this is problematic, as patients who require care should

not be compelled to remain as a patient of a provider who is not meeting their needs, particularly if the healthcare need is time-sensitive.

Comparison with other studies

As in our study, Deaf patients in a variety of other studies reported ineffective communication.^{7-9,18,21,27,106,107,119,139} One study characterized the communication difficulties experienced as ubiquitous. Ineffective communication was cited as a reason to avoid healthcare providers or to forego needed care.^{7,8,119,140} Dissatisfaction with VRI interpreting was expressed by Deaf patients in several studies.^{111,141} Deaf women were less satisfied with care than were Deaf men,¹¹¹ and patients found it difficult to access healthcare services.^{7,8,21} No studies were found that controvert the assertion that communication in healthcare settings for Deaf patients is frequently sub-par.

Limitations and strengths

No demographic information on race/ethnicity was requested from respondents. ASL responses, as a result of damaged data, were unable to be linked with the corresponding short-answer and written English responses from the same respondent. This was a convenience sample and one effect of the online recruitment and data collection method may be that the respondents had higher educational attainment than is representative of members of the Deaf community. Nevertheless, the online format and novel survey administration which allowed for narrative responses in ASL to be submitted by video was instrumental in allowing a geographically diverse sample of respondents to retain their anonymity while completing the survey. Improved generalizability across a range of urban and rural settings is a strength of the study.

Implications

Effective provider-patient communication is associated with positive health outcomes, better adherence, and patient satisfaction.¹⁴² Failure to effectively communicate can be the cause of misdiagnosis,¹⁴³ medical errors, suffering and mortality.¹⁴⁴ Our results suggest healthcare providers and staff require more education regarding their obligation to provide Deaf patients with communication that is as effective as their communication with patients who can hear. The communication preferences of Deaf patients should be solicited and honored by healthcare providers. Recognition of the impact and ineffectiveness of providing ad hoc or no interpreter is crucial to assuring quality. Deaf patients deserve equity in healthcare.

We recommend studies be conducted which describe the frequency with which Deaf patients are denied effective communication in healthcare encounters. The impact of a denial to provide accommodations for Deaf patients should be examined as related to patient adherence, satisfaction and outcomes of care.

CHAPTER FOUR: Interpreters are “too expensive and we probably won’t talk that much”: An audit study of Deaf patients’ access to basic health care

Abstract

Importance: Deaf patients who communicate in ASL may not experience effective communication in health care settings without reasonable accommodation. Front-line clinic staff, clinic administrators, or providers may not secure ASL interpreters when necessary. Clinics may be less willing to accept Deaf patients when an interpreter is requested, creating diminished access to basic health care.

Objectives: To measure the success rate of new patient appointments secured and compare reasons for unsuccessful appointment requests between Deaf patients and patients who can hear.

Design: This field experimental study employed a simulated patient (SP) call audit method. Using a patient script simulating an adult seeking to establish care, new patient appointments were requested from clinics throughout Idaho. Deaf SPs requested the provision of interpreting services at the appointment. Calls were made between June 7 and December 6, 2018.

Setting: Appointments were requested at 445 clinics (335 primary care and 111 general dentistry clinics) in Idaho from a statewide stratified random sample of providers.

Participants: Providers were randomly selected from the Idaho Medical and Dental Associations member databases. Clinics where the sampled provider reportedly practiced were eligible for the study if: 1) a screening call was successful, 2) service to the general population was offered, and 3) the practice type was either a primary care, internal medicine, pediatric medical or general dentistry clinic.

Main Outcomes and Measures: The factors were examined in association with successfully securing a new patient appointment, population density, perceived gender, clinic type, and region. A sub-analysis included reasons new patient appointments were not secured by Deaf SPs regarding interpreter services, and factors associated with that outcome.

Results: Patients who can hear were nearly two times more likely to secure new patient appointments compared to Deaf patients (AOR=1.88 95%CI 1.27-2.78). For Deaf patients, 48.2% of appointment requests failed because a request for interpretation was made. More contacts between Deaf patients and clinics was positively associated with an interpreter-related denial.

Conclusions and Relevance: The findings suggest that in a statewide representative sample, access to basic healthcare for Deaf patients is significantly reduced. A request for interpreting services, even when required for effective communication, was the most common reason appointment requests by Deaf patients failed.

Key Points

Question: Are patients who can hear more likely to secure new patient appointments than Deaf users of American Sign Language (ASL)?

Findings: In this audit study of Idaho primary care and general dentistry, clinics were sampled at a ratio of 3:1, simulated patients who can hear were nearly two times (AOR=1.88 95%CI 1.27-2.78) more likely to secure new patient appointments than Deaf simulated patients. For Deaf patients, 48.1% of appointment requests failed because a request for interpretation was made. Factors positively associated with an interpreter-related denial included dental clinic status, being female, number of contacts between simulated patients and clinic, and certain regions.

Meaning: The findings suggest that access to basic health care for Deaf patients is significantly reduced if a request for ASL interpretation is made, even when such services are required for effective communication.

Introduction

Effective communication between a healthcare provider and patient has been called the “heart and art of medicine.”¹⁴² Effective communication fosters an exchange of information between the provider and patient,¹⁴⁵ allows the provider to ask open-ended questions,¹⁴² and improves treatment outcomes.¹⁴⁶ In the case of Deaf patients who use American Sign Language (ASL) as their primary mode of communication, providers may be unable to engage in this dialogue successfully without the services of an ASL interpreter, which, according to the Americans with Disabilities Act (ADA), must be supplied if such services are necessary to ensure that communication with Deaf patients is as effective as communication with other patients.¹⁴⁷ Patients are not responsible for the cost of these services.²

Deaf patients have reported that the main communication barriers experienced in healthcare settings are the lack of ASL interpreters and the lack of use of sign language by healthcare professionals.⁵ Inadequate comprehension during healthcare encounters and the lack of engagement¹⁴⁸ may contribute to feelings of fear, mistrust, frustration²¹ or the avoidance of healthcare providers altogether.¹⁰⁷ Deaf patients have an increased likelihood of poor doctor-patient communication and reduced satisfaction with care,¹⁴⁰ may be unable to share important medical history or ask questions,⁶ or unable to establish a strong relationship with their primary care providers.¹ This can result in misunderstanding of diagnoses⁷ and treatment regimens that affect self-management and health outcomes.⁸ Communication may impact where Deaf patients seek care as they are more likely to access healthcare via the emergency department (ED), which may be due

to increased accessibility to ASL interpreters in an ED setting than in primary care settings.¹⁴⁹

Access to basic healthcare includes the formation of a trusting relationship between a provider and patient, which includes effective communication and culturally competent care.²⁶ For Deaf patients, positive healthcare encounters include the presence of medically experienced certified sign language interpreters.¹⁴⁰ Without interpreters, providers who are not fluent in ASL may be unable to appreciate subtle presentations or symptoms of conditions that require communication for assessment.¹⁵⁰

In the United States, there is no current estimate of the additional costs incurred and inadequate treatment received because of communication barriers experienced by Deaf patients, but it is estimated that for Deaf patients in the United Kingdom, the National Health Service spends £30 million annually due to avoidable poor health outcomes¹⁵¹ and needless suffering.¹³ Extrapolating this to the United States, which has approximately 5.7 times more sign language users,¹¹¹ could result in a cost-burden of approximately \$2.2 billion per year.

The need for successful communication is not limited to the patient-provider encounter. Deaf patients report difficulty making healthcare appointments,^{7,8} a failure to receive requested help from clinic staff,⁷ and an inability to successfully contact clinics independently because of communication barriers.⁸ Front desk staff may engage in gatekeeping or discriminatory actions when responding to patient requests made over the phone.¹⁵² The discrimination may be based on patient names, accent cues, or, in the case of Deaf patients, an unfamiliarity with interpreted phone calls. Deaf patients typically request healthcare appointments using the video relay service (VRS), a federally-funded

interpreting service in which the person who can hear uses spoken English over the traditional telephone and the Deaf party uses ASL via videophone which is then interpreted.¹⁵³ VRS calls often begin with an announcement by the interpreter that the call is from a person using sign language. Interaction with front desk staff can impact the rate of secured appointments¹⁵² and can reduce or increase the burden patients bear to push for effective service.¹⁵⁴

If Deaf patients believe communication was ineffective during a healthcare encounter, they may report to or file complaints with a variety of entities: advocacy organizations such as the National Association of the Deaf; disability rights advocates, state agencies, and entities that provide oversight of healthcare providers and facilities¹⁵⁵ Other accounts may be found in court records or news reports.^{156,157} However, reports of ineffective communication may not have been documented consistently, may exist only in data that is unavailable to the public, and are not consolidated in a single repository, preventing a complete understanding of the scope and severity of the problem. To date, there has been no study that documents the rate of provision of ASL interpreters when requested by Deaf patients when accessing healthcare.

Methods

The Idaho State University Institutional Review Board did not deem this study to be human subjects research as no identifiable personal information about individual patients, providers, or staff of the clinics studied was collected. All data linking providers and clinic addresses to assigned clinic IDs has been destroyed.

Design and Setting

The Idaho Council for the Deaf and Hard of Hearing (CDHH), Idaho State University, and Deaf community members from Boise, Idaho, formed a community-based participatory research collaboration. Identification of current strategies to access care, concerns, and research focus preferences were documented in focus group meetings conducted exclusively in ASL.

A sampling frame was created from board certification lists of primary care and general dentistry providers that were matched to 2,098 clinics and hospitals statewide using Google geo-location API. Of these, primary care (n=1215 57.9%) and general dentistry (n=883 42%) clinics in Idaho, 1,132 (53.9%) possessed unique clinic phone numbers. A population proportionate stratified sample which represented 7 health districts was determined and 445 clinics (39.3%) comprised of 75% primary care (n=334, oversampling) and 25% (n=111) general dentistry were eligible for study inclusion. (See Figure C) Each clinic included in the sample was called prior to the study to verify that the number was in service.

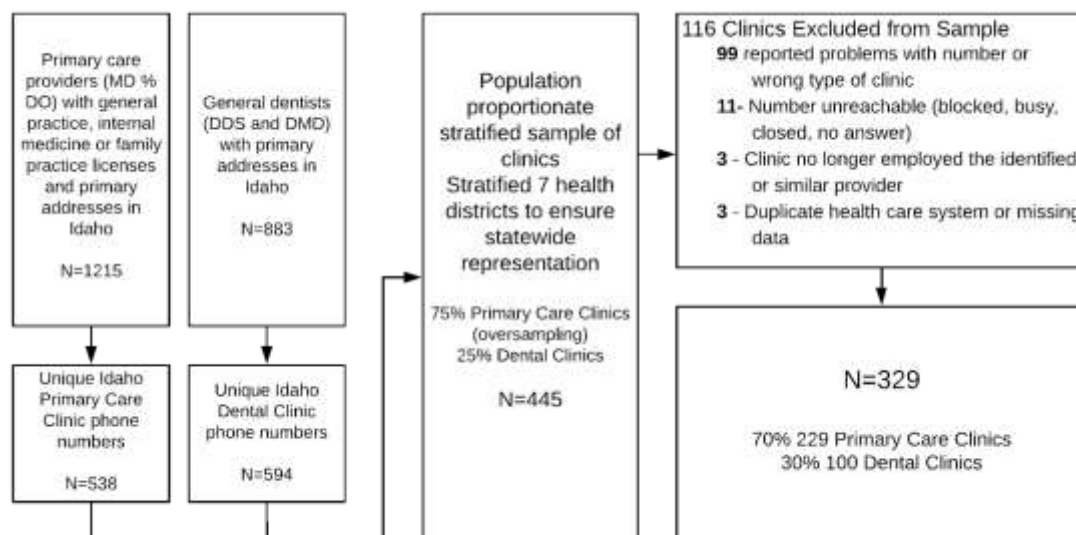


Figure D Sampling Procedure and Reasons for Clinic Exclusion

Two male and two female simulated patients (SPs) who can hear were selected, as were two male and two female Deaf SPs in order to serve as matched SPs who can hear with Deaf SPs seeking new patient appointments. The audio and/or video was recorded for each call to ensure study protocol compliance and verification of call outcome. SPs were trained in the use of a standardized script and completed test calls with supervision to ensure consistency. SPs self-selected fictitious patient names and had individual local phone numbers assigned with message capability for follow-up. SPs were assigned fictitious local addresses in each health district and Blue Cross of Idaho, employee plan, as their health insurance, although they did not provide a policy number when request, as the script stated that they had relocated recently. SPs requested appointments with the selected provider but if the provider was not accepting new patients or was unavailable within the limits set by the study, SPs asked if another provider was available, including physician assistants and nurse practitioners.

Deaf SPs received further training by Idaho CDHH and ISU in study protocol specific to the request for interpreter services. Focus group members selected the VRS provider to be used, the type and amount of self-advocacy included in the call script, and contact information for an interpreter referral service that SPs would give to clinic staff upon request or as a suggestion of a resource to call when securing interpreters. Deaf SPs verified that the sex of the VRS interpreter was consistent with their own.

There were 1,096 call records completed by SPs between June 7 and December 6, 2018. Call records included field notes as necessary. In order to minimize the inconvenience and to prevent unnecessary charges, study protocol dictated that only appointments offered that occurred at least four weeks after the initial call was made were accepted. After accepting an appointment, SPs called clinics again to cancel the appointment. Appointments were canceled with at least 2 weeks' notice to prevent charges for interpreter services and/or loss of provider availability for patient visits. The interpreter referral service partnered in the study by identifying appointment requests for Deaf SPs, providing a confirmation of services to the clinic, and ensuring no charges were incurred by clinics as a result of the request for interpreter services.

Measures

Appointments requests were considered successful if SPs who can hear were given an appointment time/date. The requests of Deaf SPs were considered successful if they were given an appointment time/date and received a confirmation that interpreting services had been secured for the appointment. Population density¹⁵⁸, sex or perceived sex, clinic type, and region were the factors examined in association with successfully securing a new patient appointment. A sub-analysis included reasons new patient

appointments were not secured by Deaf SPs regarding interpreter services, and factors associated with that outcome.

Statistical analysis

Differences in descriptive statistics using Pearson chi-square and t-tests were used for those securing new patient appointments (compared to those that did not) and among Deaf SPs those that were unsuccessful in securing a new patient appointment because of an interpreter-related reasons (compared to all other reasons). Using conditional fixed effects logistic regression in Stata (StataCorp version 13) we described the likelihood of securing a new patient appointment among our Deaf SPs compared to matched SPs who can hear. Patients were matched 1:1 by clinic identification number. Among Deaf SPs, logistic regression was used to assess demographic and call-related factors associated with having an interpreter-related reason for an unsuccessful attempt at securing an appointment. Forward regression modeling of demographic and call-related factors (entry $\alpha=0.2$; exit $\alpha=0.1$) was used with collinear variables dropped for each model.

Results

Unsuccessful appointment requests fell into three categories: protocol requirements of either the sampled clinic or study protocol; failure to meet clinic screening requirements; and interpreter-related denials. Requests were denied because providers were not accepting new patients 19.8% of the time for patients who can hear, and 18.6% of the time for Deaf patients. For 2.4% of failed appointment requests, Deaf SPs were told that the clinic did not accept their insurance, which did not occur with SPs who can hear.

Four types of interpreter-related denials were identified: a) The request for interpreter services was denied before appointment time/date was offered (28.75%); b) The request for interpreter services was denied after appointment time/date was offered (28.75%); c) Appointment and interpreter request was approved, however, no confirmation of interpreter services was given, despite follow-up attempts (22.5%); and d) De facto denials, which occurred when the Deaf SP requested interpreter services, but was not offered an appointment. Clinic staff said that they would call back with an approval or denial of the request, but failed to do so, even after two follow-up calls were made (20%). (See Figure D)

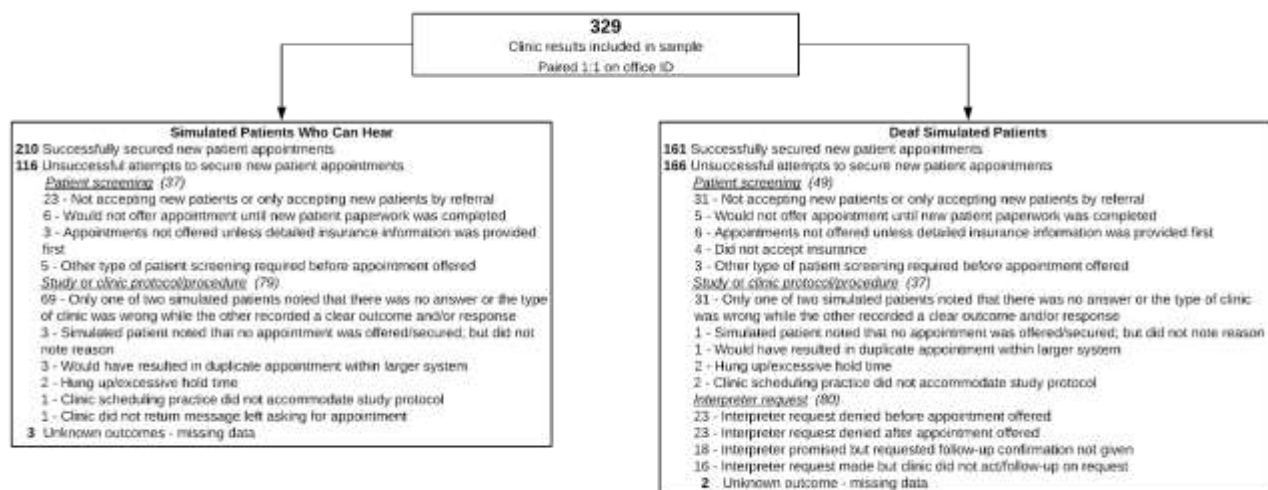


Figure E Outcomes of New Patient Appointment Requests

Approximately half of Deaf SPs were able to secure a new patient appointment (43.3%) compared to 56.6% among patients who can hear ($p < 0.001$; See Table 4.1). Attempts to secure appointments were more likely to be successful at primary care clinics (53.7%) compared to dental clinics (63.5%; $p < 0.001$). In terms of odds of success, SPs who can hear were nearly two times more likely to secure new patient appointments

compared to Deaf SPs (AOR=1.88 95%CI 1.27-2.78), after controlling for the number of contacts made and the sex of the SP.

Table 4.1 Demographic and call related factors overall and by success status for securing an appointment by Deaf simulated patients

	Overall (n=658)	Success (n=654)		Pearson chi- square/t- test
		Y	N	
Simulated patient				<0.001
Not Deaf	49.9	56.6	41.1	
Deaf	50.1	43.3	58.9	
Demographics				
Clinic type				0.020
Primary Care	69.4	74.2	65.8	
Dental	30.6	25.8	34.2	
Density				0.067
Urban (Metro MMA)	71.6	68.7	75.3	
Rural (Micro MMA or Neither)	28.4	31.3	24.7	
Region				0.526
North	21.9	21.8	21.9	
Southwest	44.8	43.1	47.0	
Southeast	33.3	35.0	31.1	
Sex				0.722
Male	48.9	49.5	48.1	
Female	51.2	50.5	51.9	
Call related				
Average # of contacts	1.24	1.23	1.26	0.568

Among Deaf SPs, 48.1% (80/166) indicated that the reason that an appointment was not secured related to requesting an interpreter. Among these, attempts to secure new patient appointments at dental clinics were more likely than primary care clinics to have an interpreter-related reason for not securing the appointment ($p<0.001$; See Table 4.2). Deaf SPs that had an interpreter-related reason for an unsuccessful attempt averaged 1.6 contacts compared to 1.2 contacts for those unsuccessful for other reasons ($p<0.001$).

Demographic factors independently and positively associated with not securing an appointment for interpreter-related reasons were being a dental clinic compared to primary care clinic (AOR 6.47 95% CI 2.90-14.69), female compared to male (AOR 2.43 95% CI 1.16-5.13), Southeast region compared to Southwest region (AOR 3.11 95%CI 1.34-7.20), and the number of times the SP made contact with the clinic (AOR 2.46 95%CI 1.29-4.69).

Table 4.2 Demographic and call-related factors associated with having an interpreter-related reason for unsuccessful attempt at accessing health care among Deaf simulated patients

	Interpreter-related reason for unsuccessful attempt (n=166)				
	Y	N	χ^2 /t- test p-value	OR	AOR*
Demographics					
Clinic type			<0.001		
Primary Care	47.5	84.7		Ref	Ref
Dental	52.5	15.3		6.12 (2.93- 12.77)	6.47 (2.90- 14.69)
Density			0.091		
Urban (Metro MMA)	67.5	79.1		Ref	-
Rural (Micro MMA or Neither)	32.5	20.9		1.79 (0.89-3.61)	-
Region			0.247		
North	20.0	22.1		1.19 (0.53-2.67)	1.10 (0.43-2.83)
Southwest	41.3	51.2		Ref	Ref
Southeastern	38.8	26.7		1.80 (0.89-3.63)	3.11 (1.34-7.20)
Sex			0.218		
Male	46.3	55.8		Ref	Ref
Female	53.8	44.2		1.61 (0.87-2.98)	2.43 (1.16-5.13)
Call related			<0.001		
# of contacts	1.6	1.2		2.53 (1.46-4.40)	2.46 (1.29-4.69)

Discussion

In this audit study of a statewide representative sample of primary care and general dentistry clinics we demonstrated that Deaf patients experience diminished access to care in both medical and dental clinic settings. Their requests to establish care are unsuccessful more frequently than requests made by patients who can hear. The requests Deaf patients made for appointments failed largely due to reasons related to the need for

interpreter services at the appointment. For Deaf patients, appointment requests were more likely to fail at the point of interpreter-related requests if the patient was female, from the Southeast region of Idaho, the request was made to a dental clinic, or if the patient had more contact with the clinic.

Access to basic health services is an essential component of access to healthcare. Patients that have a usual provider, place, and source of care experience better health outcomes and are more likely to receive preventive services and screenings.²⁶ Barriers that limit access to services likely contribute to health disparities, inadequate health literacy, and incomplete health knowledge among Deaf people.¹⁸ The decreased number of new patient appointments secured by Deaf SPs in this study underscore the challenge Deaf patients face when attempting to establish care with a provider. Deaf people have been found to have fewer physician visits,¹⁵⁹ be less likely to have visited a doctor in the preceding two years,¹⁶⁰ and are more likely to avoid healthcare providers due to lack of communication or lack of an interpreter.⁵

The Department of Justice states that sign language interpreters are generally needed for healthcare communication as common as "...taking the medical history of a patient who uses sign language..."³ and, as such, would have been necessary for effective communication at the new patient appointments requested by Deaf SPs. Healthcare entities and providers are not permitted under ADA to allow Deaf patients to participate in communication as a benefit if it is unequal to that of patients who can hear.⁹¹ It is possible that the clinic staff who responded to the patient did not make the request of interpreter services known to the provider, or neither the staff nor the provider was aware of the obligation to provide auxiliary aids and services, including interpreter services,

necessary to achieve effective communication. The clinic staff or provider may have believed that it was not their responsibility to pay for the cost of interpreter services. Deaf SPs, at times, received direction from clinic staff to bring a family member or friend to interpret for their appointment, which, unless there is an imminent threat to safety or welfare, does not comply with the ADA.³

Although it has been demonstrated that providers vary in their understanding of their legal responsibilities to patients with disabilities,¹⁶¹ clinic staff may have engaged in explicit gatekeeping¹⁵² or discriminatory treatment of the Deaf SPs. VRS interpreters do not follow a scripted greeting, and some interpreters may have informed staff that a Deaf person was calling or the staff person was able to surmise this based on background noise present during the call, since most VRS calls are made from a call center and present differently from other calls. As in another study, Deaf SPs reported being hung-up on frequently and calling back several times before their call was accepted.¹⁰⁷

The provision of interpreter services for Deaf patients is positively associated with better adherence to preventative screening recommendations,¹⁶² while, in one study, failure to provide requested interpreter services resulted in 82% of patients being unable to understand their diagnosis, 70% who did not understand the guidelines for their treatment, and 63% who chose to discontinue care.⁵ The communication preference of 83% of Deaf patients is either to have interpretation services at their appointment or a provider who is language-concordant and capable of communicating directly.¹⁶³

The National Association of the Deaf provides a consumer fact sheet instructing Deaf patients to inform providers in advance about their need for interpreting services,¹⁶⁴ but this may or may not be successful. Nearly one-third of persons with hearing loss that

participated in a survey reported that no arrangements were made to improve communication in healthcare environments, despite the fact that 93% of respondents informed providers about their hearing loss.¹⁶⁵ In our study, the number of new patient appointments where interpreter services would be provided for Deaf SPs may have been overestimated, as we categorized a promise by clinic personnel as an indication that there would be interpreter services provided had the appointment occurred. This categorization is not consistent with the findings of a previous study that indicated interpreter services were frequently promised but not provided upon arrival at the appointment.⁴

It has been suggested that although communication problems are the most significant factor affecting access to healthcare services for Deaf patients, Deaf patients needed to increase their expectation and demands of the same access to healthcare that others enjoy.¹²⁰ Our study controverts that claim, as Deaf SPs in our study expected to be accepted as new patients. Training has been provided to Deaf community members to self-advocate for accommodations in healthcare and other settings,¹⁶⁶ yet, the more contacts the Deaf SPs had with the clinic, the less likely they were to receive a new patient appointment. This suggests that training clinic staff to respond appropriately to requests for accommodations might be a more successful approach.

Dental clinics were more than six times more likely to deny a new patient request for an interpreter-related reason than primary care clinics. In Idaho, the Medicaid dental plan is administered by Managed Care of North America Dental. In their participant manual, it is affirmed that they will arrange interpreter services for either a patient or a parent or guardian of a patient at no charge.¹⁶⁷ Clinic staff may have denied the request for interpreter services because they were accustomed to a dental plan administrator

providing these services. A new patient appointment at a dental clinic typically requires a comprehensive examination, including history and a treatment plan.¹⁶⁸ The amount of communication required at a typical first appointment at a dental clinic varies significantly from that at subsequent appointments, and clinic staff may not have recognized the need for interpreter services and therefore denied the request. Further, dental clinics, unlike primary care clinics, are less likely to be affiliated with a healthcare system. Primary care clinics affiliated with a healthcare system may have access to interpreter services through the parent organization.

CHAPTER FIVE: CONCLUSION

Conclusion and Discussion

The collective findings of the articles presented in this dissertation depict what is rightly regarded by some Deaf patients as a healthcare system that is unwelcoming, inequitable and discriminatory. Although there are segments within the Deaf community who find their care to be satisfactory, the reported experiences of absent communication and disregard of other Deaf patients should be more than sufficient reason to immediately address issues of patient safety for Deaf people. Healthcare research has a long history of exploitation and/or exclusion of Deaf people^{11,14} and it is only in the recent past that ethical research principles have been articulated and applied to the Deaf community.^{16,22,74,98}

To begin, many studies on the health of Deaf people have been conducted in ways that result in inaccurate and/or incomplete findings or embrace a paradigm that reflects a deficit model of Deaf culture.^{59,85} In Chapter Two, an achievable approach to ensuring Deaf participation and direction in research was presented. This model can be applied in settings where researchers must collaborate remotely, even though some hearing researchers found that to be an insurmountable barrier.¹⁶⁹

The history and importance of a Deaf epistemology in research was highlighted and introspective evaluation of the impact of the etic researcher was examined. A new survey delivery model was discussed, and future surveys soliciting input from Deaf

patients should follow suit by always offering fully bilingual survey instruments that accept narrative responses in ASL—to do less is discriminatory.

Researchers who seek to fully embrace equity in healthcare research with Deaf populations have been given a tool to evaluate their readiness to do so. Researchers conducting qualitative research with Deaf populations should ensure it is carried out in a context that recognizes the characteristics and value of Deaf culture, and receive funding from agencies/entities that recognize goals other than the eradication of the pathology of hearing loss.

In an ideal world, places of public accommodation would enthusiastically comply with the ADA and other laws, making their services available to people with disabilities with the same level of quality provided to the general population. Although improvements have been made, discrimination still exists in healthcare settings, Deaf people receive disparate care, and the complaint activated mechanism intended to provide enforcement has been not only unsuccessful, but burdensome for those who must use it to address inequities.¹³⁸ While cross-sectional or quota studies of Deaf patients in the United States on a number of specific issues in healthcare such as lung cancer screenings,⁶ health literacy,¹⁷⁰ and specific disparities in health outcomes,^{20,171} descriptions of exact barriers to communication and lack of accommodations in healthcare settings was not fully reported.

Chapter Three provides rich descriptions of the experiences of Deaf patients when seeking healthcare or requesting sign language interpreters as an accommodation. Information from this study provides further evidence of a fragmented enforcement and reporting system¹⁷² that fails to successfully incentivize healthcare entities to comply

with ADA, resulting in repeated refusals to ensure effective communication. More than a third of Deaf patients report that securing interpreter services for appointments is difficult. The survey verified other reports of Deaf patients avoiding healthcare encounters^{107,140} and foregoing needed care.^{8,119} Patients promoted the use of medically-qualified, professional interpreters as an accommodation that ensured full participation, as was cited in other studies.^{7,140} But in contrast to many patient wishes, provision of ad hoc and unqualified interpreters was commonly reported and was associated with understanding a provider less than those that had professional interpreters provided.

Reports of failure to provide interpreter services have long been available, but until studies presented in this dissertation were conducted, the reports of the overt discrimination experienced by Deaf people seeking to become patients or receive effective communication had been limited to the anecdotal.^{18,107,140,157,173,174} While much has been written on the importance of qualified medical interpreters and the training and skills they need,¹⁷⁵⁻¹⁷⁷ the failure to provide interpreters as an accommodation had not been empirically verified. The failure by healthcare entities to provide reasonable accommodations for communication in compliance with the law when requested by Deaf patients comes as a surprise to many well-intentioned providers. There was no empirical support that this phenomenon was widespread. The audit study featured in Chapter Four provides strong evidence and quantification of this phenomena that will allow for study replication and further documentation of this problem.

Although Deaf patients in the past had reported believing that the provider ultimately decided to provide or refuse accommodations for encounters,¹⁷⁸ the audit study indicated that it might be more common that this decision is made without full

involvement of the provider. My findings suggest that clinic staff need to be educated on legal obligations of providers, in agreement with another study which pointed out the difficulties experienced by patients when interacting with clinic staff.⁷

Implications & Recommendations

Based on these studies, I make three specific recommendations. I first recommend that the National Institutes of Health recognize Deaf people as a health disparity population and begin funding research into the disparate health outcomes, care, and literacy experienced by Deaf people. The second recommendation is that US Department of Health and Human Services (HHS), Office of Civil Rights (OCR), be authorized to impose civil monetary penalties on healthcare entities that fail to comply with the ADA. Lastly, I suggest that all healthcare profession program accreditation standards include curriculum content requirements which introduce and reinforce knowledge of civil rights laws, specifically the ADA and Title IV of the Civil Rights Act of 1964 and evaluation the application of this knowledge to their future profession.

Recognize Deaf Communities as Health Disparity Populations

Currently, the majority of research funding from the National Institutes of Health which supports public health surveillance and studies regarding healthcare outcomes, utilization, and communication of Deaf people is awarded by the National Institute on Deafness and Other Communication Disorders (NIDCD). NIDCD's focus area is to "...bring national attention to the disorders and dysfunctions of human communication."¹⁷⁹ As noted in Chapter Two, even the name of the agency has been described as objectionable to members of the Deaf community because of the medicalized view of Deaf people.²⁴

Another NIH entity, the National Institute on Minority Health and Health Disparities (NIMHD), defines their eligible health disparity populations as: “Blacks/African Americans, Hispanics/Latinos, American Indians/Alaska Natives, Asian Americans, Native Hawaiians and other Pacific Islanders, socioeconomically disadvantaged populations, underserved rural populations, and sexual and gender minorities.”¹⁹ Studies of health disparities in disabled populations, including Deaf populations, is limited to studies of “intersecting social statuses” such as racial/ethnic minorities living in rural vs. urban areas or “subgroups within a health disparity population” e.g. racial/ethnic minorities with disabilities.¹⁸⁰ This Schylla and Charybdis dilemma puts inclusive and respectful researchers in the position of either accepting funding to investigate Deaf communities from a pathological standpoint or limiting interventions to only a segment of the Deaf population, when it should be available to the general population of Deaf individuals.

Recognition of Deaf people as members of an ethnic group would also allow the recognition of Deaf communities as a health disparity population and allow appropriately-funded research to be conducted. This approach has been taken in the United Kingdom, where Deaf populations are recognized in this manner¹⁵¹ and in France, where Deaf communities are served by special health outreach programs designed specifically to address their unique needs.¹⁸¹

Authorization to Assess Civil Monetary Penalties When Healthcare Entities Fail to Comply with ADA

Since 2003, HHS OCR has been responsible for enforcing the privacy and security rules that are included in the Health Insurance Portability and Accountability Act

(HIPAA).¹⁸² Although HIPAA was signed into law in 1996, it was not fully implemented until 2003, the same year 45 CFR 160 passed, which allowed the assessment of civil money penalties on entities that violated HIPAA standards.¹⁸³ Although the effectiveness of the penalties has been debated, from a layperson's evaluation, the ability to locate the appropriate entity with whom to lodge a complaint is far easier than it is to file a complaint of ADA non-compliance. When one wishes to file a HIPAA complaint, a simple Google search will lead you to the HHS website for complaints.

In the survey study featured in Chapter Three of this dissertation, respondents reported repeated failures to provide legally-required accommodations. Feelings of futility and resignation were present when considering courses of action available to Deaf patients when violations of ADA occurred. In support of their frustration, consider the following example of an alleged violation of the ADA and the complaint process a Deaf patient would have to grapple with:

Mariana, a 54-year old monolingual Deaf user of ASL living in Tucson, Arizona, is seen at a hospital-affiliated urgent care center for heartburn. She is insured by Medicaid. While at the clinic, she requests a sign language interpreter by writing a note to the receptionist. After being taken into an examination room, the nurse writes Mariana a note, saying that she "should have brought a family member to interpret, because we don't have one here." Mariana writes notes to the provider, and is told to take acid reflux medication. She returns home, but after three hours, Mariana goes to the emergency room, where an in-person interpreter is provided. After examination and tests, it is confirmed that Mariana has experienced a mild heart attack. Mariana believes that she was discriminated against and not provided effective communication.

In order to address the non-compliance of ADA, Mariana's choices consist of at least the following:

1. Contact the hospital ADA coordinator and file a complaint, since the urgent care clinic is affiliated with the hospital.

2. File a complaint with the Centers for Medicare & Medicaid Services Consumer Information and Oversight Division, because she is a Medicaid recipient.
3. File an Office of Civil Rights Complaint with the Department of Health and Human Services, as the urgent care clinic is covered until Title VI of the Civil Rights Act and Section 1557 of ACA, as Mariana is a individual with LEP.
4. File an ADA complaint with the Department of Justice.
5. Retain an attorney and file a lawsuit under ADA or Title VI.
6. Contact the Arizona Commission for the Deaf and Hard of Hearing and request that a Deaf specialist help file a complaint.
7. Contact the Arizona Center for Disability Law, the federally-funded protection and advocacy agency, to receive help filing a complaint.
8. File a complaint with The Joint Commission.
9. Request that the Arizona Attorney General, Office of Civil Rights, intervene, investigate, and/or litigate her complaint.
10. File a grievance with the Arizona Health Care Cost Containment System.
11. File a complaint against the nurse with the Arizona State Board of Nursing.

This example provides evidence of the various avenues available to Deaf patients when attempting to address discrimination in health care settings and to ensure provision of sign language interpreters. Unfortunately, it also provides evidence of a fragmented system of enforcement that requires expert help, the ability to read and respond to

directions written at high-school or higher levels, which is arguably difficult to understand for native speakers of English, let alone individuals whose first language is ASL. Self-advocacy in this case also requires the ability to determine the most effective entity with which to file based on a description of the responsibilities of the entity and/or knowledge of which agency to file with depending on which compliance mandate was violated. For all of these options, there are no instructions in ASL available.

From a cursory review, it would also appear that HHS OCR is more successful in enforcing compliance. As of May 31, 2020, HHS reported receiving over 235,201 HIPAA complaints and initiating 1,003 compliance reviews and imposed a civil money penalty in 25 cases totaling \$116,303,582.00.¹⁸⁴ From 2000 to 2010, the Department of Justice, Civil Rights Division entered into 36 settlement agreements or consent decrees for complaints due to discrimination in health care settings. These 36 cases were from situations involving persons with any disability, (e.g. seven cases were due to the fact that the medical provider did not have an accessible examining table.) Of these 36 settlement agreements or consent decrees, 24, or 66% involved Deaf patients requesting interpreter services.¹³⁸

In 2012, U.S. Attorney's offices and the Department of Justice's Civil Rights Division launched the "Barrier-Free Health Care Initiative", which specifically targeted enforcement efforts in effective communication with Deaf patients, physical access to medical care for persons with mobility issues, and equal access for people living with HIV/AIDS. Of the 44 settlement agreements since the initiative's inception, 34 or 77% of the settlement agreements cited a failure to provide interpreter services or otherwise effectively communicate with Deaf patients.¹¹⁶ Despite a much lower volume of cases, it

does not appear that the enforcement efforts from 2000-2010 were successful in incentivizing compliance. Empowering HHS to assess civil money penalties and assume responsibility for enforcement would encourage compliance, and an economy of scale could be achieved, since HHS also currently accepts complaints from Medicare/Medicaid recipients who allege ADA violations. With this additional responsibility, HHS should also be compelled to make the process accessible to Deaf patients and provide instructions in ASL.

Health Sciences Educational Programs Curricular Content Requirement

In the audit study (Chapter Four), the personnel identified as discriminating against Deaf patients or requiring that Deaf patients provide their own interpreter for appointments varied. There were occasions when the clinic staff appeared to make this decision without consulting the provider. This lack of awareness of legal responsibility puts the viability of clinics at risk, but, more importantly, decreases the access to healthcare for Deaf patients. Although there are some bad actors who may intentionally discriminate and refuse to comply with the ADA, it is equally possible that with education, healthcare entities would comply and provide effective communication. There have been instances reported in which providers realized the value added by interpreting services and insisted on providing them in future interactions with Deaf patients.⁹¹

There is personnel turn-over in every business. In healthcare environments, front desk and office managers change as a matter of course. However, if providers were educated in their legal obligations and given an understanding of how effective communication accommodations are consistent with principles of patient-centered care, they would be able to train their staff to appropriately respond to requests by Deaf

patients for interpreter services. This need not be limited only to physicians, but should become a curriculum element for all health science professions.

While there may be certain health science education professions that require knowledge of civil rights laws, currently, upon examination of the curriculum content standards of United States medical schools that award MD degrees, there is no specific accreditation standard that addresses this legal obligation. In the 2020 Standards of Accreditation of Medical Education Programs Leading to the MD Degree, 12 standards for accreditation are articulated.¹⁸⁵ Standard Seven addresses curricular content, and the self-study guide directs documentation of cultural competence and health care disparity curricular content¹⁸⁶ reporting to include the information seen in Figure F, below:

7.6 Cultural Competence and Health Care Disparities

The faculty of a medical school ensure that the medical curriculum provides opportunities for medical students to learn to recognize and appropriately address biases in themselves, in others, and in the health care delivery process. The medical curriculum includes content regarding the following:

- The diverse manner in which people perceive health and illness and respond to various symptoms, diseases, and treatments
- The basic principles of culturally competent health care
- Recognition of the impact of disparities in health care on all populations and potential methods to eliminate health care disparities
- The knowledge, skills, and core professional attributes needed to provide effective care in a multidimensional and diverse society

Supporting Data

Table 7.6-1 Cultural Competence	
Provide the names of courses and clerkships that include objectives related to cultural competence in health care. For each, list the specific topic areas covered. Schools using the AAMC Tool for Assessing Cultural Competence Training (TACCT) may use the "Domains" table as a source for these data.	
Course/Clerkship	Topic Area(s) Covered

Table 7.6-2 Health Disparities, Demographic Influences, and Medically Underserved Populations			
Provide the names of courses and clerkships where explicit learning objectives related to the listed topics areas are taught and assessed. For each course/clerkship indicate with an "X" which area(s) is/are included.			
Course/Clerkship	Topic Area(s) Covered		
	Identifying and Providing Solutions for Health Disparities	Identifying Demographic Influences on Health Care Quality and Effectiveness	Meeting the Health Care Needs of Medically Underserved Populations

Table 7.6-3 General Medical Education - Preparation for Residency					
Provide school and national comparison data from the AAMC Medical School Graduation Questionnaire (AAMC GQ) on the percentage of respondents who <i>agree/strongly agree</i> (aggregated) that they are prepared in the following area to begin a residency program: <i>Prepared to care for patients from different backgrounds.</i>					
AAMC GQ 2019		AAMC GQ 2020		AAMC GQ 2021	
School %	National %	School %	National %	School %	National %

Table 7.6-4 Adequacy of Education in Caring for Patients from Different Backgrounds								
Provide data from the ISA by curriculum year on the number and percentage of students who responded <i>N/A, dissatisfied/very dissatisfied</i> (combined), and <i>satisfied/very satisfied</i> (combined) with the adequacy of education in caring for patients from different backgrounds.								
Medical School Class	Number of Total Responses/Response Rate to this Item		Number and % of N/A Responses		Number and % of Combined Dissatisfied and Very Dissatisfied Responses		Number and % of Combined Satisfied and Very Satisfied Responses	
	N	%	N	%	N	%	N	%
M1								
M2								
M3								
M4								
Total								

Narrative Response

- a. Provide two examples of how the curriculum prepares medical students to be aware of their own gender and cultural biases and those of their peers and teachers.

Figure F LCME Cultural Competence and Health Care Disparities Curriculum Standard 7.6 copyright 2020, Association of American Medical Colleges and American Medical Association

Civil rights laws and their implications for practice and patient care and not a required element of the curriculum standard. If the health science profession students received this information as a part of their required training, they could serve as the lynchpin that ensures ongoing accessibility in healthcare environments for Deaf patients.

Data Dissemination & Future Research Directions

The pilot grant that funded the articles found in Chapters Three and Four also funded a retrospective review of complaints filed regarding healthcare access and interpreter requests with the Idaho CDHH. The resulting article titled “Ask and ye shall not receive: Interpreter-related access barriers reported by Deaf users of American Sign Language”, was accepted for publication in *Disability and Health Journal* in April of 2020 (doi.org/10.1016/j.dhjo.2020.100932) The trial-and-error process of dissemination of this article to both the scientific community and, more importantly, to the Deaf community, informed the process for future dissemination.

In the cover letter included with the manuscript submission for the retrospective complaint review article, a request was made to allow for an ASL version of the manuscript in the online supplemental materials section. However, the file size limit for supplemental materials would not allow a high-resolution video of sufficient length to be submitted. After review of Althoff¹⁸⁷ and Quintana,¹⁸⁸ with support from Idaho CDHH, it has been determined that we will produce our own executive summary of each publication in ASL and post to Idaho CDHH’s social media accounts and send executive summaries in written English to elected officials and contacts. Twitter will be used to promote the dissemination of the results of all publications and include a short ASL excerpt with each tweet. A recent executive summary and graphical abstract of the audit

study results (Chapter 4) was created for the National Association of the Deaf's Accessible Telehealth Task Force, upon request. (See Appendix D)

Preliminary results of the audit study were presented in a poster session at the Association of Medical Professionals with Hearing Loss conference in Baltimore, Maryland in June of 2019, and further results and training on the same subject were presented to the Idaho College of Osteopathic Medicine on February 14, 2020, co-presented by myself and Steven Snow. Our proposal "Communication in Healthcare: Access, Research and YOU!" for a podium session at the National Association of the Deaf's conference in Chicago 2020 was accepted, prior before the cancellation of the conference due to COVID-19. I was scheduled to present a poster in August of 2020 at the Conference of Interpreter Trainer's conference in Minneapolis, MN titled, "They don't handle finding interpreters": An audit study of Deaf patients and access to basic healthcare" before the conference was cancelled as well due to COVID-19.

I am a member of the Mountain West Clinical and Translational Research – Infrastructure Network (CTR-IN) Ambassador Translational Research in Progress cohort. On May 8, 2020, I gave a "Research in Progress" presentation to members of the group and their advice to me was that I submit an R21 grant proposal to the National Institute on Deafness and Communication Disorders to increase the sample of primary care and dental clinics to three state-wide samples. To that end, on August 24, 2020, I plan to submit a grant application for pre-submission review by the CTR-IN Advance to Funding mock grant review which includes expert editing and participation in a teleconferenced mock study session.

One important addition to the next grant proposal is the inclusion of the dissemination plan and a detailed community dissemination process that includes overlapping phases such as planning, outreach, content development, interactive presentations and follow-up, as suggested in the literature.¹⁸⁹ In our case, we will need to adapt plans to accommodate a community that is not located in one geographic area, and provide activities and a flexible approach that allow for community feedback and involvement remotely.

Sign language interpreter education programs should enhance their curriculum with instruction designed to teach students to evaluate their readiness to interpret in healthcare settings. Currently, there are two programs in the U.S. that provide specialization in healthcare interpreting: one in Minnesota at the undergraduate level, and a second graduate-level program in Rochester, NY. Both have excellent reputations, but it is unrealistic to expect that graduates of interpreter education programs will not provide services in healthcare settings, as this is a common community setting. Research in the most effective ways to partner with the Deaf community to enhance health literacy presentation in interpreted encounters as well as research into the role of interpreters in meeting community goals to lessen health disparities among Deaf people is necessary.

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APPENDIX A

Table A.1 Contributor Roles Taxonomy (CRediT)

Appendix A

Table A.1. CRediT — Contributor roles taxonomy

Header: This taxonomy provides a high-level classification of the diverse roles performed in the work leading to a published research output in the sciences. Its purpose is to provide transparency in contributions to scholarly published work, to enable improved systems of attribution, credit, and accountability.

The classification includes, but is not limited to, traditional authorship roles. That is, these roles are not intended to define what constitutes authorship. Rather, the roles are intended to apply to all those who contribute to research that results in scholarly published works, and it is recommended that all tagged contributors be listed, whether they are formally listed as authors or named in acknowledgements.

An individual contributor may be assigned multiple roles, and a given role may be assigned to multiple contributors. When there are multiple people serving in the same role, a degree of contribution may optionally be specified as 'lead', 'equal', or 'supporting'. It is recommended that corresponding authors assume responsibility for role assignment, and that all contributors be given the opportunity to review and confirm assigned roles.

Term	Definition
Conceptualization	Ideas; formulation or evolution of overarching research goals and aims
Methodology	Development or design of methodology; creation of models
Software	Programming, software development; designing computer programs; implementation of the computer code and supporting algorithms; testing of existing code components
Validation	Verification, whether as a part of the activity or separate, of the overall replication/reproducibility of results/experiments and other research outputs
Formal Analysis	Application of statistical, mathematical, computational, or other formal techniques to analyze or synthesize study data
Investigation	Conducting a research and investigation process, specifically performing the experiments, or data/evidence collection
Resources	Provision of study materials, reagents, materials, patients, laboratory samples, animals, instrumentation, computing resources, or other analysis tools
Data curation	Management activities to annotate (produce metadata), scrub data and maintain research data (including software code, where it is necessary for interpreting the data itself) for initial use and later reuse
Writing – Original Draft	Preparation, creation and/or presentation of the published work, specifically writing the initial draft (including substantive translation)
Writing – Review & Editing	Preparation, creation and/or presentation of the published work by those from the original research group, specifically critical review, commentary or revision – including pre- or post-publication stages
Visualization	Preparation, creation and/or presentation of the published work, specifically visualization/data presentation
Supervision	Oversight and leadership responsibility for the research activity planning and execution, including mentorship external to the core team
Project Administration	Management and coordination responsibility for the research activity planning and execution
Funding acquisition	Acquisition of the financial support for the project leading to this publication.

From: Brand A, Allen L, Altman M, Hlava M, Scott J. Beyond authorship: Attribution, contribution, collaboration, and credit. *Learn Publ.* 2015;28(2):153. doi:10.1087/20150211

APPENDIX B

Deaf Healthcare Communication Survey

Appendix B

Deaf Healthcare Communication Survey Items

1. Do you use ASL as your primary mode of communication?

ASL means not only "pure" ASL, but also includes SEE signs, PSE, or other sign language. If we say "ASL, that means that you mostly use sign language to communicate.

2. What is your current age?

- A. 18-24
- B. 25-34
- C. 35-44
- D. 45-54
- E. 55-64
- F. 65 or more

3. In which state do you currently reside?

50 states, District of Columbia and "I do not reside in the US"

4. Would you consider where you live to be:

- Urban
- Rural

5. What is your marital status?

- A. Single
- B. Married/Partnered
- C. Divorced/Widowed
- D. Separated
- E. Other

6. Do you currently consider yourself to be:

- A. Male
- B. Female
- C. Other

7. What is the highest level of education you completed?

- A. Less than 9th grade
- B. Some high school (9th-12th grade)
- C. High school graduate or GED
- D. Some college
- E. College graduate

8. How do you define yourself as a D(d)eaf person?

- A. Deaf
- B. deaf
- C. Hard of Hearing

- D. Late (D)deafened
- E. DeafBlind

Option to type in own answer
 Option to record video answer in ASL

If the person selected DeafBlind (above), the following message was displayed:

If you define yourself as DeafBlind, please contact the principal investigator, Elizabeth Schniedewind, with any requests for accommodation. Her email is schneli1@isu.edu We would be happy to make the survey accessible to those with vision issues. (This message also displayed in ASL)

9. How long have you been Deaf?
- A. Since birth
 - B. Before 3 years old
 - C. Between 4 and 11 years old
 - D. Between 12 and 18 years old
 - E. After 19 years old

We will now ask you about your experiences using and communicating with health professionals. Health professionals in this context are doctors (MD or DO), nurses, mid-level providers (physician Assistants and Nurse Practitioners), and/or dentists.

10. When did you see a health professional last?
- A. In the last month
 - B. Between 2 and 6 months ago
 - C. Between 6 and 12 months ago
 - D. Over one year ago

11. In the past year, how many times in total have you seen a health professional?
- A. 0 (none)
 - B. 1 time
 - C. 2 times
 - D. 3 times
 - E. 4 or more times

12. Where do you usually see a health professional for your health?
- A. Private office
 - B. Public clinic
 - C. Emergency room
 - D. Hospital

Option to type in own answer
 Option to record video answer in ASL

13. For most of your medical appointments, does anyone go with you?

- A. No, I go alone
- B. Yes, a professional interpreter
- C. Yes, a family member
- D. Yes, a hearing friend
- E. Yes, a Deaf/HoH friend

Option to type in own answer

Option to record video answer in ASL

14. How do you primarily communicate with health professionals?

- A. ASL - Family member interprets
- B. ASL - Friend interprets
- C. ASL - Professional interpreter
- D. Writing
- E. Lip-reading
- F. Gestures

Option to type in own answer

Option to record video answer in ASL

If A, B, D, E was selected or a respondent-created choice was created, this follow-up question was displayed after question 21 was answered:

Before, you said that you didn't primarily communicate with your healthcare professional by using an ASL interpreter. Why?

Some examples of why people wouldn't communicate by using an interpreter

Option to be:

- I prefer to go alone or write
- I don't feel comfortable with an interpreter or don't trust interpreters
- It's too difficult to get an interpreter or I don't know how
- Health professional refuses to get an interpreter or I don't want to pay for the interpreter myself

15. During your appointments, how much do you think your healthcare professional understands you?

- A. Everything
- B. Almost everything
- C. Some
- D. Very little
- E. None

16. During your appointments, how much do you think you understand what your healthcare professional tells you?

- A. Everything

- B. Almost everything
- C. Some
- D. Very little
- E. None

17. Have you ever needed healthcare but didn't pursue getting an appointment with a provider?

- Yes
- No

If 17 was answered "Yes", the following was shown in English and ASL:

If you didn't pursue getting an appointment, why? Here are some examples of reasons people need healthcare but don't try to get an appointment: it won't help to see a provider; too hard to see provider; provider won't get interpreter; didn't have money or insurance, etc.

18. When you need to select a new healthcare professional, what is most important? Rank these in order. You can also add your own answer and tell us how important it is.

Click and drag the answers to put them in your order.

- Accepts my insurance
- Will provide professional interpreters
- Friends recommendation
- Positive online reviews
- Has appointment soonest
- Qualifications
- Distance from me

- Option to type in own answer
- Option to record video answer in ASL

19. In general, how satisfied do you feel with your medical care?

- A. Very satisfied
- B. Satisfied
- C. Fair
- D. Unhappy
- E. Very unhappy

The next questions are about interpreters at appointments with healthcare professionals.

20. Who schedules your healthcare appointments?

- A. Me
- B. A hearing family member

- C. A hearing friend
- D. A Deaf friend or family member

Option to type in own answer

Option to record video answer in ASL

21. Do you or the person that schedules your appointments request that the healthcare professional provide an interpreter for your appointments?

- A. Always
- B. Most of the time
- C. Sometimes
- D. Rarely
- E. Never

22. How difficult is it to get a professional interpreter for medical appointments?

- A. Very difficult
- B. Difficult
- C. Neither difficult or easy
- D. Easy
- E. Very easy
- F. Doesn't apply to me

23. Have you ever gone to an appointment when the healthcare professional said there would be an interpreter provided but when you went, there wasn't an interpreter there?

- Yes
- No

If the answer to 23 was yes, then the following was displayed:

23a. If you went to an appointment and the healthcare provider said there would be an interpreter provided but an interpreter wasn't there, how often has this happened?

- A. Every time
- B. Most of the time
- C. Sometimes
- D. Rarely
- E. Once

24. Who primarily pays for interpreting services at your appointments?

- A. The health professional
- B. The hospital
- C. Me
- D. My insurance company
- E. Unknown

Option to type in own answer

Option to record video answer in ASL

25. Have you ever asked your friends which healthcare professional(s) will provide interpreters when selecting a provider?

Yes

No

26. Are there any experiences you would like to share about the subject of interpreters for healthcare appointments?

Yes - type in answer

Yes - record answer in ASL

No

APPENDIX C

Video Quote Links and Selected English Translations

Appendix C

Video Quote Links and Selected English Translations

Quote V.1

So, on the whole, when I think about the healthcare system, I'm not thrilled. I do get care, yes, but the care I get there comes at a price: damage to my self-image and self-worth. I'm constantly reminded that my culture, Deaf culture, and who I am as a Deaf person doesn't matter at all. I'm treated like I'm subhuman.

[\[return\]](#)

Quote V.2

My ears are fine. You should be looking down here, not at my ears. They would just go on and on, asking me about how I became deaf and putting more information into my file. C'mon, it's not an audiology appointment!

[\[return\]](#)

Quote V.3

It feels demeaning. Every time I'm in that environment, it's just like this ongoing series of microaggressions coming at me again and again. It's awful.

[\[return\]](#)

Quote V.4

Communication barriers are sometimes what keeps me from going to the doctor. I can go and try to communicate, but I don't know if I'm getting the answers or not.

[\[return\]](#)

Quote V.5

Doctors have an obligation to their patients to make sure that their needs are met so that they can get cared for. And in that situation, I needed an in-person interpreter. But instead, it became an argument and I had to go somewhere else to get care.

[\[return\]](#)

Quote V.6

I tell them that I need an interpreter, and they tell me they will get one. But when I get there, there's no interpreter. This happens over and over and over again. I end up waiting so long--too long.

[\[return\]](#)

Quote V.7

The second reason that I don't like to go to the doctor is because they make you wait for an appointment for a long time to get the interpreter, or they say, "No, we won't see you immediately because you have to have an interpreter or I have to wait forever for the interpreter to show up. Yes, it's good to have an interpreter, but I end up being the one that waits such a long time or I can't get immediate care when I need it.

[\[return\]](#)

Quote V.8

When I go into the doctor's office to make an appointment, the people at the front desk say, "Oh no, we can't provide an interpreter. You're going to have to bring your own interpreter. We're not responsible, you are." *Sigh* And they say, "You're going to have to pay." Me, I'm the one that's going to have to pay? No.

[\[return\]](#)

Quote V.9

I had to go to the hospital to receive radiation treatment. And so I asked for an in-person interpreter instead of video remote interpreting because I knew that they would have to turn it on and off and that it wouldn't be available the whole time. I also knew that they couldn't use the computer in the radiation suite.

But, the scheduling person said the hospital policy required that you use VRI. I tried to tell them it wouldn't work, but they didn't listen. So on the day of the treatment, we went into the radiation suite and, of course, the VRI didn't work, it couldn't be used in that room. So they had to take me out to the hallway and have the VRI interpreting, and then they brought me back in and they made an incision but they had to ask a question, and they couldn't have an interpreter.

So they had the nurse write it out on the white board and I struggled to write down the answer, and then finally we could move ahead. But if they would have just gotten a live interpreter like I asked in the first place, I wouldn't have had to go through that.

[\[return\]](#)

Quote V.10

I'm very comfortable with self-advocating for my needs. I know when I'm not understanding, and am not reluctant to speak up. I can tell someone that I need them to clarify and I am comfortable with being assertive. I'm the kind of patient who knows how to get what I need from an interaction without an interpreter.

[\[return\]](#)

Quote V.11

I end up weighing the severity of my physical needs against the emotional pain that I'm going to face when I ask for an interpreter. And I think I'd rather just put up with it than go through the frustration of asking for an interpreter and getting one that isn't qualified or having to beg to get an interpreter.

[\[return\]](#)

Quote V.12

There was a doctor who was really willing to take their time and write with me, understanding that writing might mean there was a negative impact on our communication but was still willing to put in the extra work necessary to communicate well. For example, we would be writing, and they sensed from my responses that I wasn't completely understanding, and so they would tell me I had to paraphrase what they had just told me. I was surprised when they asked for that, but they were a good doctor, and would ask for more details until they were sure that they got it, even using gestures. It was a good experience.

[\[return\]](#)

Quote V.13

I've been going to this healthcare provider for awhile, and I finally stopped and dropped the whole thing. The reason why is things happened over and over again with this doctor.

I'd have to write back and forth and the doctor wouldn't provide me an ASL interpreter. I asked him repeatedly, and for some reason, they didn't think I was serious, and they didn't pay attention to my needs. And so I finally--I looked around for other doctors, but they were really far away. And this was the only provider that was close. I made repeated appointments and asked them for an interpreter; they said no every time.

I'd...I explained to them, "The ADA requires that you provide for me in that way and provide an interpreter." And they refused. I went over it again and again with them. And finally I dropped it. I just completely decided "Well, I'm just gonna have to bear with the pain I have. I'm just gonna have to accept it and live my life with pain."

[\[return\]](#)

Quote V.14

For many years, the same interpreter provided interpreting services for me. I live in a small town, and for ten years I worked with the same interpreter. But then she caused me to lose almost everything, including my job, because of her behavior.

After that, I told the doctor's office that I needed to have a different interpreter and they said that wasn't possible because of their contract with the interpreting agency. I explained that it was a conflict of interest for her to continue providing services to me, but they didn't listen. I asked them to work it out with the interpreting agency they contracted with, and they said no.

The interpreter should not have been permitted to continue working with me. For the past year and a half, I haven't been able to have an interpreter for my appointments,

because the office says she has to interpret for me. I'm exasperated by the unending struggle. I was fine with her interpreting until that situation.

Now I can't tell if the doctor is really stuck in a contract, or if they have some back-room deal with the interpreter. But I know for sure that I need a different interpreter. I've tried and the office won't budge--I can't bring myself to go to appointments anymore.

But when I let other providers know that she needed to be replaced, even though there aren't many interpreters, almost all of them honored my request, and asked the interpreter referral service to send another interpreter. The hospital provided a different interpreter, and my cardiologist did, too; but my primary care provider wouldn't get someone else.

They refuse and say it is because of the contract. Contract or no, it is not right that I am forced to accept her services. I shouldn't have to, and I can't; it's so frustrating.

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APPENDIX D

Visual Abstract of Audit Study Findings

Because of discrimination, access to basic healthcare is reduced for Deaf people

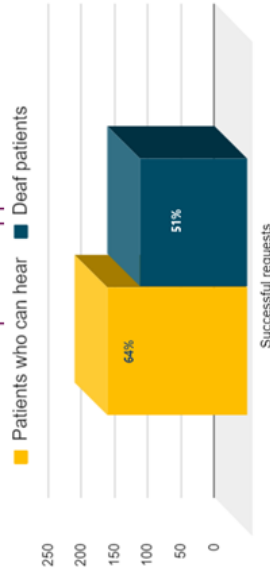
It is common knowledge within the Deaf community that they experience serious barriers when trying to access healthcare. Some clinics will not accept them as patients and others won't provide interpreter services when asked, even if the patient needs an interpreter to understand basic health information.

Deaf people often receive care with insufficient communication, resulting in mis- and under-diagnosis of health conditions. Their health knowledge may be limited because they can't fully communicate with their provider. And now we know that they are right about the discrimination they say they experience.

Deaf people deserve to be accepted as patients, have full communication, and participate in their healthcare.

In a study of 445 randomly selected primary care and dental clinics throughout Idaho, simulated patients used a script and asked for a new patient appointment. Deaf patients called through the video relay service and asked that an interpreter be provided at their appointment.

"I'd like a new patient appointment"



Patients who can hear were **almost two times more likely** to secure new patient appointments than Deaf patients (AOR=1.88 95%CI 1.27-2.78)



Idaho State University



Even though all patients had the same insurance, only Deaf patients were sometimes told it wasn't accepted.

Self-advocacy didn't guarantee full access

The **more contact** a Deaf patient had with a clinic after explaining the ADA requirement for effective communication, the more likely it was that their appointment request would be **unsuccessful** due to the request for an interpreter.

Why were appointment requests unsuccessful?

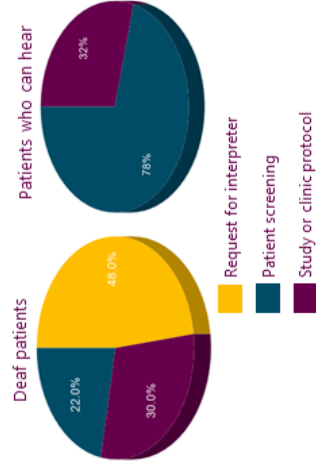


Figure G Visual Abstract of Audit Study Findings