COMMUNICATION ACCESS AMONG PEOPLE WHO ARE DEAF OR HARD OF HEARING IN NORTH CAROLINA

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BACKGROUND AND OBJECTIVE

Challenges faced daily by deaf ASL-speakers are poorly understood by healthcare providers and policymakers

Objective: Describe barriers to quality communication between deaf ASL-speakers and their healthcare providers and strategies to address them

INTERVIEW METHODS: COMMUNITY FORUMS AND INDIVIDUAL INTERVIEWS

Data: Interviews were conducted during community forums in Lexington, Raleigh, Wilson, and Morganton, June 2018 to February 2019, video-recorded for coding and translated into English (n=54)

Discussion prompt: What is your experience in communication with your doctors? Would you describe a typical experience? Were you satisfied?

Methods: Open-coding to identify salient themes

INTERVIEW RESULTS: SAMPLE CHARACTERISTICS

	N (%)/Mean
Age	54
Sex	
Female	35 (65)
Male	19 (35)
Race	
White	42 (78)
Black	10 (19)
Other	2 (0)
Education	
High school or less	40 (75)
College	8 (15)
Graduate degree	5 (9)
Hearing status	
Deaf or Deaf-Blind	46 (85)
Hard-of-Hearing	8 (15)
Primary form of communication	
Sign Language or Cued Speech	52 (96)
Speech-read/speak	2 (4)

INTERVIEW RESULTS: THEMES

Themes	Percent of Responses
Video Remote Interpreting (VRI)	98%
Live interpreters	91%
Writing back and forth	54%
Scheduling/rescheduling appointments	24%
Lip-reading	19%
Interpreter not showing up	17%
Hospital contracts	15%
Communication access in the lobby	9%

INTERVIEW RESULTS: VIDEO REMOTE INTERPRETING

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

- *VRI interpreters are difficult to follow or understand*
- *The doctor and nurse talked to each other while the VRI screen was turned away from me*
- *VRI is a waste of time*

INTERVIEW RESULTS: VALUE OF A LIVE INTERPRETER

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

A live interpreter

- *conveys more feeling and understanding of what we communicated*
- *shows more action with facial and body expression*
- *is effective and efficient*

INTERVIEW RESULTS: WRITING NOTES

Writing back and forth sometimes caused a mental block. It is hard for me to express my feelings or thoughts when writing back and forth. It is much easier to express my feelings and thoughts in my own ASL through live interpreters.

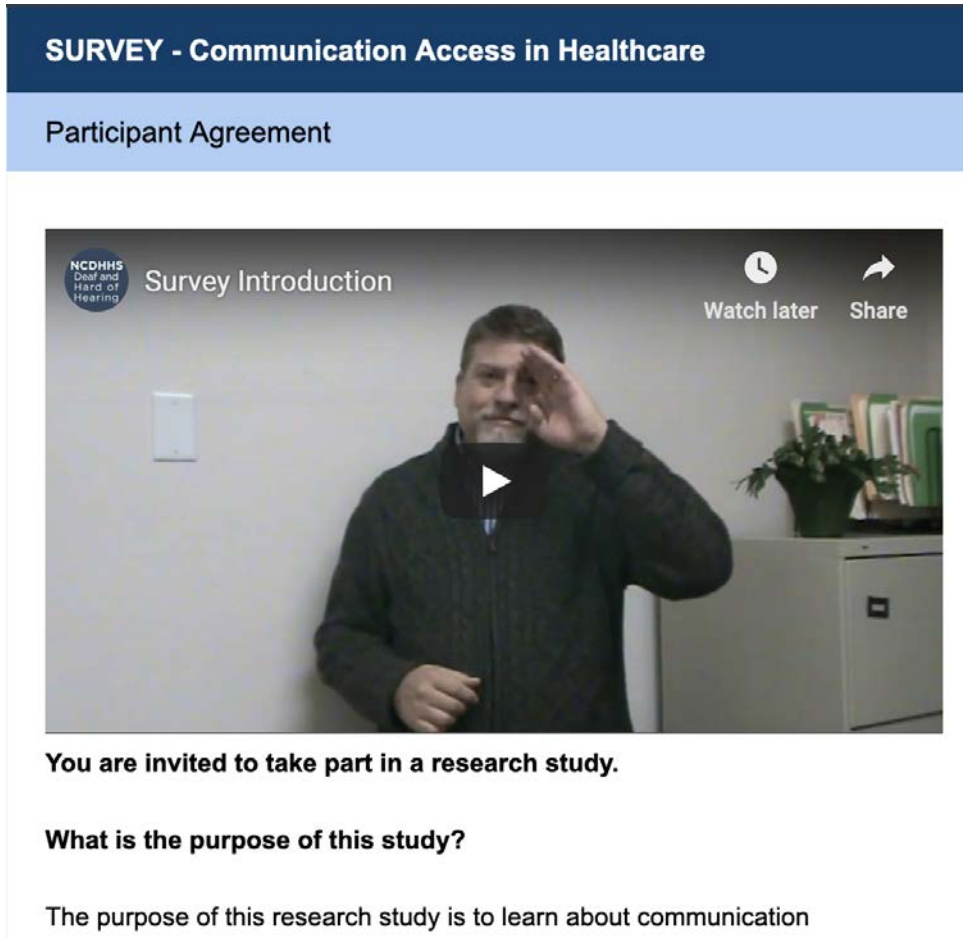
I need live interpreters, not writing back and forth because I don't understand English. They gave me notes. [sighs]

INTERVIEW RESULTS: SCHEDULING

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

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

SURVEY METHODS: WEB-BASED SURVEY



Participants: Convenience sample of people who prefer ASL as their primary form of communication who are on the mailing lists of the 7 Regional Centers of the DSDHH

Data collection: Web-based survey with embedded ASL video clips, May 2018-March 2019 (n=189)

Analytic methods: Logit models to explore relationships between communication, satisfaction and unmet need for care

SURVEY RESULTS: SAMPLE CHARACTERISTICS

2. What is your age?

- ○ 18 to 24
- ○ 25 to 34
- ○ 35 to 44
- ○ 45 to 54
- ○ 55 to 64
- ○ 65 to 74
- ○ 75 or older

	N (%)
Age group	
18 to 24	6 (3.2)
25 to 34	18 (9.5)
35 to 44	41 (21.7)
45 to 54	46 (24.3)
55 to 64	42 (22.2)
65 to 74	27 (14.3)
75 or older	9 (4.8)
Sex	
Female	143 (75.7)
Male	46 (24.3)
Race	
White	161 (85.2)
Black	16 (8.5)
Other	10 (5.3)
Education	
High school or less	84 (45.0)
College	43 (22.5)
Graduate degree	62 (32.5)
Insurance (N=166)	
Medicaid	31 (18.7)
Medicare	73 (44)
Blue Cross/Blue Shield	84 (50.6)

SURVEY RESULTS: SAMPLE CHARACTERISTICS

	N (%)
Hearing status	
Deaf	153 (81.0)
Deaf-Blind	9 (4.8)
Hard-of-Hearing	27 (14.3)
Primary form of communication	
Sign Language or Cued Speech	156 (82.5)
Speech-read/speak	22 (11.6)
Write notes	8 (4.2)
Satisfaction with doctor/provider communication	
Not satisfied/difficult to communicate	18 (10.8)
Somewhat satisfied	61 (36.7)
Very satisfied/easy to communicate	87 (52.4)

SURVEY RESULTS: FORM OF COMMUNICATION WITH CLINICIANS

	Preferred	Actual
Professional sign language interpreter	102 (61.4)	68 (41.0)
Speech-read/speak	18 (10.8)	24 (14.5)
Write notes	14 (8.4)	31 (18.7)
Relative or friend as interpreter	6 (3.6)	6 (3.6)
Sign language or cued language directly	3 (1.8)	16 (9.6)
Other	23 (13.9)	21 (12.7)

SURVEY RESULTS: DISSATISFACTION WITH COMMUNICATION

Factors associated with dissatisfaction with communication (N=166)

	Odds Ratio	95% CI	P-value
Male	1.49	0.36 - 6.21	0.58
Education More than high school	1.09	0.14 - 8.46	0.93
Rural location	0.52	0.09 - 2.87	0.45
Live alone	6.44	1.50 - 27.71	0.01
Insurance			
Medicaid	1.34	0.29 - 6.23	0.71
Medicare	1.18	0.25 - 5.58	0.84
Blue Cross/Blue Shield	0.74	0.14 - 3.83	0.72
Usual source of care			
Not personal doctor	2.27	0.49 - 10.51	0.30
Preferred method of communication			
Sign language directly or via interpreter	11.61	1.75 - 76.98	0.01
Provider's method of communication			
Sign language directly or via interpreter	0.16	0.04 - 0.57	<0.01

Controls for age, race

SURVEY RESULTS: UNMET NEED FOR CARE

Factors associated with unmet need for care (N=166)

	Odds Ratio	95% CI	P-value
Male	0.09	0.01 - 0.91	0.04
Education More than high school	0.02	0.00 - 0.21	<0.01
Rural location	0.34	0.06 - 1.79	0.20
Deaf or deaf-blind	3.36	0.28 - 40.85	0.34
Live alone	1.15	0.20 - 6.73	0.87
Insurance			
Medicaid	0.79	0.13 - 4.67	0.79
Medicare	1.64	0.33 - 8.19	0.55
Blue Cross/Blue Shield	4.96	0.71 - 34.54	0.11
Usual source of care			
Not personal doctor	42.37	6.89 - 260.73	<.01
Preferred method of communication			
Sign language directly of via interpreter	3.67	0.41 - 33.00	0.25
Provider's method of communication			
Uses sign language directly or via interpreter	0.41	0.07 - 2.35	0.31

Controls for age, race

SUMMARY

ASL users prefer to use a professional sign language interpreter to communicate with clinicians

- Most actually use some other form of communication
- Half of respondents were not completely satisfied with communication and people express dissatisfaction with video remote interpreting

People who prefer to use sign language and who live alone are more likely to report dissatisfaction with communication

- Those who actually use sign language with their clinician are less likely to report dissatisfaction
- Having family who may support communication also helps

People who go to a personal doctor are less likely to report unmet need for care

- People who have an on-going relationship with their doctor may have identified a form of communication that works

LIMITATIONS AND NEXT STEPS

Study samples were small, highly educated and connected to the NC Division of Services for the Deaf and Hard of Hearing

- Communication access is likely worse for others

North Carolina could learn more from a larger, structured survey

Current efforts by the University of Kansas and UNC Chapel Hill to establish a longitudinal National Survey on Health Reform and Disability may be an efficient strategy to generate high quality data

IMPLICATIONS FOR NORTH CAROLINA

- North Carolina needs to put in place strategies to assure communication access
- At this point, video remote interpreting is not working
- Establishing a relationship with a personal doctor may help in making communication preferences known and respected

Pharmaceutical Outcomes and Policy

Examining effectiveness and costs of medications, how patients take medications, and how policies affect health outcomes

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