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BRIEF REPORT

Collaboration With Deaf Communities to Conduct Accessible Health Surveillance

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Introduction: Populations of deaf sign language users experience health disparities unmeasured by current public health surveillance. Population-specific health data are necessary to collaboratively identify health priorities and evaluate interventions. Standardized, reproducible, and language-concordant data collection in sign language is impossible via written or telephone surveys.

Methods: Deaf and hearing researchers, community members, and other stakeholders developed a broad computer-based health survey based on the telephone-administered Behavioral Risk Factor Surveillance System. They translated survey items from English to sign language, evaluated the translations, and filmed the survey items for inclusion in their custom software. They initiated the second Rochester Deaf Health Survey in 2013 (n=211). Analyses (conducted in 2015) compared Rochester Deaf Health Survey 2013 findings with those of the Behavioral Risk Factor Surveillance System with the general adult population in the same community (2012, n=1,816).

Results: The Rochester Deaf Health Survey 2013 participants' mean age was 44.7 (range, 18–87) years. Most were deaf since birth or early childhood (87.1%) and highly educated (53.6% with ≥4 years of college). The median household income was <$35,000. The prevalence of current smokers was low (8.1%). Nearly all (93.8%) reported having health insurance, yet barriers to appropriate health care were evident, with high emergency department use (16.2% with two or more past-year visits) and 22.7% forgoing needed health care in the past year because of cost.

Conclusions: Community-engaged research with deaf populations identifies strengths and priorities, providing essential information otherwise missing from existing public health surveillance, and forming a foundation for collaborative dissemination to facilitate broader inclusion of deaf communities.

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INTRODUCTION

Populations of deaf sign language users experience health disparities, yet are rarely included in public health surveillance.[1] Population-specific health data are necessary to collaboratively identify public health priorities and subsequently evaluate targeted interventions. Standardized, reproducible, and language-concordant data collection in American Sign Language (ASL) is not possible via written or telephone surveys.[1,2] Rochester, NY has a large population of deaf ASL users. In 2004, a community–academic partnership[3] in Rochester identified the lack of health data as a barrier to selecting population-specific health priorities with deaf

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ASL users. To collect these data, this partnership became the foundation of the Rochester Prevention Research Center/National Center for Deaf Health Research (RPRC/NCDHR). RPRC/NCDHR has been funded by the Centers for Disease Control and Prevention's Prevention Research Centers Program since 2004. The first RPRC/NCDHR core research project was to develop and pilot accessible public health surveillance, called the 2008 Rochester Deaf Health Survey (RDHS-2008). RDHS-2008 was based on the telephone-administered Behavioral Risk Factor Surveillance System (BRFSS). RPRC/NCDHR compared RDHS-2008 results with data from the local general population BRFSS, and worked with communities, public health, and other stakeholders to select priorities for further research.[4] With the RDHS-2008, RPRC/NCDHR established the feasibility of including deaf ASL users in public health surveillance, and began the process to translate[5] that research into accessible public health practice.

METHODS

Deaf and hearing researchers, community members, public health practitioners, and other stakeholders, including new partners brought together by a Centers for Disease Control and Prevention Community Transformation Grant, worked together to develop the second version of RDHS. RPRC/NCDHR revised and added survey items based on RDHS-2008 findings and stakeholder priorities. As with RDHS-2008, RPRC/NCDHR translated survey items from English to sign language, evaluated the translations with back translations and cognitive interviews, and filmed the survey items for inclusion in RPRC/NCDHR custom video-enabled survey software.[4,6] The second RDHS contained 94 questions, and RPRC/NCDHR began fielding the survey in 2013. RPRC/NCDHR recruited deaf adults to take RDHS-2013 through RPRC/NCDHR community committees, deaf community organizations, e-mail, social media, posters, and face-to-face interactions during community events. RDHS-2013 was taken by 211 individuals from the Rochester metropolitan statistical area over 13 months.

The RPRC/NCDHR compared RDHS-2013 findings with findings from the local BRFSS collected via random digit dialing in Monroe County (MC), NY in 2012 (n=1,816).[7] RPRC/NCDHR conducted analyses in 2015, using SAS (version 9.4) survey procedures to adjust for possible biases introduced by telephone survey methodology, and computed descriptive summary statistics (means or proportions) with 95% CIs. Non-overlapping CIs indicated a significant difference in comparisons of RDHS-2013 and MC/BRFSS-2012 findings.[4] RPRC/NCDHR hosted community forums to share findings from the RDHS-2013, RDHS-2008, and MC/BRFSS-2012. Members of Rochester deaf communities and other stakeholders contributed to interpretation of survey findings.

The University of Rochester IRB determined the RDHS-2013 to be surveillance and not research.

RESULTS

The RDHS-2013 participants' mean age was 44.7 (range, 18–87) years. Most were highly educated (53.6% with ≥4 years of college). The median household income was <$35,000 (Table 1). Most (87.1%) were deaf since birth or early childhood. Table 2 presents selected data related to prior research findings and community and other stakeholder priorities.

DISCUSSION

The high educational attainment in RDHS-2013 is consistent with RDHS-2008 and is atypical of deaf communities elsewhere.[4,8,9] RDHS-2013 educational attainment was also high compared with MC/BRFSS-2012, yet the median income of RDHS-2013 was lower than that of MC/BRFSS-2012. The high education attainment with low income in RDHS-2013 is also consistent with RDHS-2008 findings, and warrants further research.[4,10]

Low prevalence of current smoking among adults deaf since birth/childhood is consistent with RDHS-2008[4] and findings from U.S. national data,[11] but it is not universal. A study that worked with deaf patient samples with a lower median income and lower educational attainment than the RDHS samples found a high prevalence of current smokers.[9] Research with deaf communities to understand smoking may inform interventions to reduce smoking with other populations.

In discussions with deaf community members about smoking, RPRC/NCDHR learned that some people perceived that marijuana use was more common than cigarette smoking. RPRC/NCDHR included marijuana use in RDHS-2013 and the findings support the perceptions of relatively high marijuana use (Table 2). The experience reinforces the lesson that work with communities is helpful to identify important health topics worthy of further study.

The RPRC/NCDHR explored community and stakeholder reports of high emergency department use and found support with RDHS-2013, in which 16.2% reported at least two visits in the past year (Table 2). By comparison, in the 2013 National Health Interview Survey, 6.9% of U.S. adults reported two or more visits, as did 15.0% of U.S. adults below the poverty level.[12] RPRC/NCDHR also found that many RDHS-2013 participants (22.7%) reported forgoing health care because of cost, despite the high rate of having health insurance (93.8%). Research should examine factors that predispose, enable, and impede access to and use of healthcare services,[8] and then work in partnership with deaf communities to develop and evaluate culturally appropriate and communication-accessible interventions to enhance access to health care, public health programs, and community preventive services.

Findings presented here highlight the importance of accessible public health surveillance and the need to

Table 1. Demographic Characteristics: Rochester Deaf Health Survey 2013 and Monroe County BRFSS Telephone-based Survey 2012

Characteristic	Deaf Health Survey (*n*=211)	Monroe County BRFSS (*n*=1,816)
Age, years		
Mean (95% CI)	44.7 (42.4, 47.1)	47.2 (46.0, 48.4)
Range	18–87	18–94
Male	42.6 (35.9, 49.4)	47.4 (44.3, 50.6)
Race		
White	82.1 (76.7, 87.6)	79.1 (76.5, 81.7)
African American	5.1 (2.0, 8.2)	12.6 (10.5, 14.7)*
Asian/Pacific Islander	2.5 (0.3, 4.8)	2.8 (1.5, 4.0)
American Indian/Alaska Native	1.5 (0.0, 3.3)	0.4 (0.0, 0.8)
Other or multiple races	8.7 (4.7, 12.6)	5.1 (3.7, 6.4)
Hispanic	2.0 (0.0, 4.0)	5.9 (4.5, 7.3)*
Household income		
<$20,000	39.8 (32.1, 47.4)	11.9 (9.9, 13.9)*
$20,000–$35,000	21.7 (15.3, 28.2)	23.6 (20.8, 26.5)
$35,000–$75,000	22.4 (15.9, 28.9)	33.9 (30.8, 37.1)*
>$75,000	16.1 (10.4, 21.9)	30.6 (27.4, 33.8)*
Highest level of education		
Less than high school diploma	3.1 (0.6, 5.5)	6.6 (4.9, 8.3)
High school graduate or equivalent	9.7 (5.5, 13.9)	22.9 (20.2, 25.6)*
Some college/2-year degree	33.7 (27.0, 40.3)	28.1 (25.3, 31.0)
College graduate/4 years+	53.6 (46.5, 60.6)	42.4 (39.3, 45.5)*
Marital status		
Married	28.9 (22.4, 35.3)	45.3 (42.2, 48.4)*
Divorced	16.5 (11.2, 21.8)	10.0 (8.5, 11.6)
Widowed	2.6 (0.3, 4.8)	7.4 (6.4, 8.5)*
Separated	1.0 (0.0, 2.5)	3.2 (2.2, 4.2)
Never married	38.1 (31.2, 45.0)	27.8 (24.6, 31.0)*
Member of unmarried couple	12.9 (8.1, 17.6)	6.3 (4.5, 8.0)*
Deaf-related demographics		
Age at onset of becoming deaf		
Born deaf	61.9 (55.0, 68.8)	—
Age <1 year	10.8 (6.4, 15.2)	—
Age 1–3 years	14.4 (9.4, 19.4)	—
Age 4–10 years	5.7 (2.4, 9.0)	—
Age 11–18 years	1.0 (0.0, 2.5)	—
Age 19 years or older	0.0 (0.0, 0.0)	—
I don't know	6.2 (2.8, 9.6)	—
Mother, father, or siblings are deaf	31.5 (24.9, 38.0)	—
Usher syndrome	2.0 (0.0, 4.1)	—

Note: Values are % (95% CI) unless otherwise noted. Percentages may not sum to 100 because of rounding.
*Indicates a significant difference between sample groups (CIs do not overlap).
BRFSS, Behavioral Risk Factor Survey.

reach all populations. RDHS-2013, the second RDHS, provides the opportunity to assess change compared with the first RDHS, including changes related to community-selected priority topics based on RDHS-2008 findings (obesity, partner violence, and suicide attempts). RDHS-2013 also provides an opportunity to further examine some topics in RDHS-2008.[4,10,13–15] RPRC/NCDHR and the MC Department of Public Health work together on survey item selection and timing of surveys. This ongoing collaboration permits comparison of RDHS findings with those of the local general population BRFSS. Measuring community health changes over time provides feedback on interventions, and empowers Rochester deaf populations to make informed decisions about health based on their own data, an opportunity already available to other local populations.[7]

Table 2. Selected Findings: Rochester Deaf Health Survey 2013 and Monroe County BRFSS Telephone-based Survey 2012

Selected findings	Deaf Health Survey (*n*=211)	Monroe County BRFSS (*n*=1,816)
Current smoker	8.1 (4.4, 11.9)	16.0 (13.5, 18.4)*
Marijuana use in past 30 days	14.6 (9.7, 19.4)	6.6 (4.6, 8.7)*
Weight classification by BMI		
Neither overweight nor obese (≤24.9)	39.6 (32.9, 46.3)	34.0 (30.9, 37.1)
Overweight (25.0–29.9)	30.9 (24.6, 37.3)	36.3 (33.2, 39.5)
Obese (≥30.0)	29.5 (23.2, 35.7)	29.6 (26.8, 32.5)
Ever attempted suicide	13.8 (9.0, 18.6)	NA
Attempted suicide in past 12 months	1.5 (0.0, 3.2)	0.5 (0.1, 1.0)
Have health insurance	93.8 (90.6, 97.1)	92.8 (91.0, 94.5)
Forgo health care due to cost in the past 12 months	22.7 (17.0, 28.5)	8.1 (6.3, 9.9)*
Used emergency services 2 or more times in the past 12 months	16.2 (11.2, 21.2)	NA
Intimate partner violence		
Ever been emotionally abused	24.0 (17.9, 30.0)	NA
Past 12 months emotionally abused	5.6 (2.4, 8.9)	NA
Ever been physically abused	20.1 (14.5, 25.7)	NA
Past 12 months physically abused	3.5 (0.9, 6.1)	2.9 (1.4, 4.4)
Ever been forced to have sex	13.2 (8.4, 18.0)	NA
Past 12 months forced to have sex	1.0 (0.0, 2.4)	0.3 (0.0, 0.7)

Note: Values are % (95% CI). Percentages may not sum to 100 because of rounding.
*Indicates a significant difference between sample groups (CIs do not overlap).
BRFSS, Behavioral Risk Factor Survey; NA, not asked.

Limitations

The data presented here likely underestimate the disparities experienced in Rochester and elsewhere. There are limitations to comparing RDHS-2013 and MC/BRFSS-2012. The local BRFSS data are weighted to represent the general population; there are no similar population data to weight the survey data for the population characteristics of deaf adult ASL users or adults who are deaf since birth/childhood. The high education level of the RDHS-2013 participants suggests that RPRC/NCDHR's sample is not representative of deaf populations. The RDHS is taken at a place (often not at home) on a touchscreen kiosk computer, whereas the BRFSS is a telephone interview often taken while at home. The winter of 2013–2014 presented a recruitment challenge for RDHS but not for BRFSS, and may have biased the RDHS-2013 sample to exclude people with mobility limitations or other health conditions.

CONCLUSIONS

Community-engaged research with deaf populations identifies strengths and priorities, providing essential information otherwise missing from existing public health surveillance, and forming a foundation for collaborative translation and dissemination of accessible public health programs to facilitate broader inclusion of deaf communities. Including deaf populations in public health surveillance is essential to achieve the *Healthy People 2020* goal to promote health with people with disabilities.

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