Health literacy in the Deaf population: A modified REALM (Rapid Estimate of Adult Literacy in Medicine)

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Introduction
Health literacy is the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions, for themselves and their families. Low health literacy is associated with poor health outcomes. Adults deaf since childhood and deaf adults who primarily communicate in American Sign Language (ASL) are at particular risk for low health literacy, in part related to the likelihood of low English literacy and limited “fund of information.”

Measures of health literacy have not been validated or developed with deaf adults.

Measure
The Rapid Estimate of Adult Literacy in Medicine (REALM) is commonly used in research and clinical settings to measure health literacy with hearing English language users. REALM respondents are asked to read aloud 66 English words, compiled from patient education materials and intake forms in primary care settings. The REALM 66 words are ordered based on pronunciation difficulty. For individuals with normal hearing, accurate word pronunciation is well correlated with reading comprehension. The total number of correctly pronounced words is compared to four grade-level normative categories. Scores lower than “ninth grade and above” are considered indicative of low health literacy.

Methods
We examined reported comprehension of the REALM health literacy words in a sample of deaf adults whose primary mode of communication was sign language.

We modified the REALM instructions by asking respondents to circle the words they understood and cross-out words they did not. The Flesch-Kincaid grade level score for these instructions is 2.8.

We scored this “modified REALM” based on the number of words a respondent reported understanding. The study was approved by the University of Rochester Research Subjects Review Board.

Results
We solicited research subjects during an afternoon community fair during Deaf Awareness Week. ASL-fluent researchers answered questions about the research and consent. We solicited research subjects during an afternoon community fair during Deaf Awareness Week.

Data collection included the modified REALM, a single page English questionnaire on sociodemographics & biometric measures (height, weight, waist circumference, and blood pressure).

We gave each participant a paper with their own biometrics along with an explanation of the normal range of each measure. Referral information for deaf-accessible medical practices was available for interested participants.

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Demographics
Below are demographics for the 61 adults who indicated that they were deaf (the other choices were “hearing” and “hard of hearing”). Only 57 set the modified REALM.

Age range……………………21-89
Age mean ± SD……………….45.2 ±13.0
Age median…………………N (%) Female 30 (49.2%) Age-at-onset of deafness Born/0-3 51 (83.6%) 4-18 4 (6.6%) 19+ 2 (3.3%) DK 4 (6.6%) Best language sign language 47 (77.0%) voice only 1 (1.6%) writing 1 (1.6%) sign & another 12 (19.7%) Deaf parent(s) 12 (19.7%)

Limitations

Many deaf participants had difficulty with health terms on the REALM, including 21.7% of participants with college degrees who earned scores comparable to REALM scores below the ninth grade level, considered indicative of low health literacy.

Deaf participants and hearing English language users appear to have different patterns of difficulty with REALM terms. Hearing people generally are more likely to have difficulties at the end of the REALM list, whereas deaf participants did not exhibit that pattern. The pattern of universally correct also appears different with our deaf participants than would be expected of hearing English language users.

Participants with lower scores were more likely to be overweight or obese, which suggests that the modified REALM may be measuring a characteristic associated with health risks or poor health outcomes.

Discussion
Future research should explore how to measure health literacy with adults deaf since childhood and deaf adult ASL-users. Collaboration amongst deaf and hearing researchers, clinicians, educators and other community members can identify & address disparities in access to health information, healthcare and health research.

Conclusions

Future research should explore how to measure health literacy with adults deaf since childhood and deaf adult ASL-users. Collaboration amongst deaf and hearing researchers, clinicians, educators and other community members can identify & address disparities in access to health information, healthcare and health research.

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