Health literacy in the Deaf population: A modified REALM (Rapid Estimate of Adult Literacy in Medicine) Steven Barnett MD & Robert Q Pollard PhD

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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.

Data Collection

We solicited research subjects during an afternoon community fair during Deaf Awareness Week.

ASL-fluent researchers answered questions about the research and consent

Data collection included the modified REALM, a single page English questionnaire on sociodemographics & health, and 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.

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 completed the modified REAI M

112/12/11				
Age range 21-89				
Age mean ± SD45.2 ±13.0				
Age median	Age median46			
	N (%)			
Female	30 (49.2%)			
Age-at-onset of deafnes	S			
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%)			
Education				
<12th grade	2 (3.3%)			
HS grad	10 (16.4%)			
AA	13 (21.3%)			
BA/BS	15 (24.6%)			
Master	17 (27.9%)			
doctoral	3 (4.9%)			

Instrument National Center on Deaf Health Research 2004 Deaf Awareness Week Research Project Medical Word Quiz PLEASE READ THESE MEDICAL WORDS. IF YOU DO UNDERSIAND WHAT THE WORD MEANS, CIRCLE THE WORD.

IF YOU DO NOT	UNDERSTAND WHAT THE W			
MEANS, CROSS OUT THE WORD.				

Fat	Fatigue	Allergic
Flu	Pelvic	Menstrual
Pill	Jaundice	Testicle
Dose	Infection	Colitis
Eye	Exercise	Emergency
Stress	Behavior	Medication
Smear	Prescription	Occupation
Nerves	Notify	Sexually
Germs	Gallbladder	Alcoholism
Meals	Calories	Irritation
Disease	Depression	Constipation
Cancer	Miscarriage	Gonorrhea
Caffeine	Pregnancy	Inflammatory
Attack	Arthritis	Diabetes
Kidney	Nutrition	Hepatitis
Hormones	Menopause	Antibiotics
Herpes	Appendix	Diagnosis
Seizure	Abnormal	Potassium

Results

Syphilis

Nausea

Directed

Hemorrhoids

Anemia

Obesity

Impetigo

Osteoporosis

Bowel

Asthma

Recta

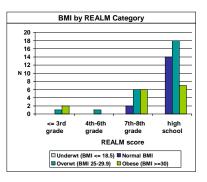
Words Least Frequently Understood

	LM c and Word = "most difficult")	Number Who Did Not Understand (n=57)	Number with College Degrees Who Did Not Understand (n=46)
66,	Impetigo	42	31
48,	Colitis	18	12
62,	Potassium	16	8
44,	Directed	16	12
65,	Osteoporosis	14	8
25,	Jaundice	14	9
22,	Incest	13	9
64,	Obesity	12	5
56,	Gonorrhea	12	6
55,	Constipation	11	6
21,	Rectal	11	7
7.	Smear	11	6

Results

Words Unive	ersally Understood
Rank	Word
3	Pill
5	Eye
6	Stress
9	Germs
10	Meals
49	Emergency
52	Sexually

REALM Scores by Education Level					
Education	on REALM Raw Score Range				
level	[Corresponding Grade Equivalent]				Total
	0-18	19-44	45-60	61-66	
	[< 3 rd]	[4 th - 6 th]	[7 th - 8 th]	[9 th -HS]	
No answer	0	0	0	1	1
< 12 th gr	1	0	1	0	2
HS grade	1	1	4	2	8
Associate	1	0	6	6	13
Bachelor	0	0	2	12	14
Master	0	0	1	15	16
Doctorate	0	0	0	3	3
Total	3	1	14	39	57



Limitations

We did not test comprehension but relied on respondent's report of comprehension. We may be overor underestimating the respondents' knowledge of English language health terms.

This was a highly educated sample. We should be cautious about generalizing these findings to the larger Deaf community.

Discussion

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.

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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We presented aspects of this study elsewhere:

Pollard RQ, Barnett S (2005). Health literacy in the deaf population: A preliminary study. American Public Health Association Annual Meeting, Philadelphia (December 13).

Barnett S, Pollard RQ (2005). Metabolic syndrome risks: A pilot study with deaf adults who communicate with American Sign Language. American Public Health Association Annual Meeting, Philadelphia (December 12).

Barnett S, Pollard RQ (2005). Health literacy & metabolic syndrome risks: A pilot study with deaf adults who communicate with American Sign Language. Academy Health Annual Research Meeting, Boston (June 27).

Pollard RQ, Barnett S (2005). Deaf Awareness Week health survey results. Deaf Rochester News, 9(3), 10-11.

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