Health-Related Vocabulary Knowledge Among Deaf Adults

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Background: Many deaf individuals are at increased risk for fund-of-information deficits, including deficits in health-related information. Research on health information knowledge, an aspect of health literacy, demonstrates an association between low health literacy and health disparities in many populations. Deaf individuals are at particular risk for low health literacy, but no research has been conducted on this topic. ***Objective:*** To investigate health-related vocabulary knowledge in a sample of deaf adults. ***Measure:*** A task based on the Rapid Estimate of Adult Literacy in Medicine (REALM). ***Participants:*** Fifty-seven deaf adults reported whether they did or did not comprehend 66 health-related terms from the REALM. Of the participants, 81% possessed a college degree. ***Results:*** Thirty-two percent of the deaf participants earned scores on the modified REALM task comparable to REALM scores considered indicative of low health literacy. The pattern of words that were least commonly and most commonly understood differed from normative expectations of hearing REALM respondents. ***Conclusions:*** This highly educated deaf participant sample demonstrated risk for low health literacy. The general deaf population is likely at even higher risk for health problems associated with low health literacy.

Keywords: deafness, REALM, age of onset, sign language, health literacy, reading

Approximately 4.8 million Americans report being unable to hear or understand speech (Ries, 1994). Deaf individuals who communicate via American Sign Language (ASL) make up a sizable portion of this population. ASL is the primary language of an estimated 200,000–500,000 Americans (Barnett, 2005; Marschark, 1997) as well as of deaf Canadians. ASL is characterized by

phonologic, syntactic, grammatical, and dialogic properties that differ markedly from English (Valli, Lucas, & Mulrooney, 2005). The majority of ASL users are individuals who have been deaf since birth or early childhood. People deaf since birth or early childhood commonly struggle with English literacy; it is estimated that the average deaf high school senior reads at the fourth-grade level (Holt, 1993). Low literacy contributes to what Pollard (1998) has termed *fund-of-information deficit,* that is, a distinct limitation in one's factual knowledge base in comparison to the general population, despite normal IQ and educational attainment. For deaf individuals, many of whom already struggle with English literacy, access to information is made even more difficult because radio, television and movie soundtracks, overheard conversations, public address announcements, and other auditory sources of information are also not accessible, further increasing the risk of fund-of-information deficit. Among the many topics to which a fund-of-information deficit may pertain are health-related topics. In the health care field, there has been an increasing focus on how knowledge deficits regarding illnesses, their symptoms and causes, illness prevention, treatment options and risks, medicines, and related matters may contribute to health disparities. The term most frequently used to describe this particular knowledge base and the skills associated with it is *health literacy.*

Health literacy has become an important topic in medical research, practice, and public policy (Davis & Wolf, 2004; Mayer & Villaire, 2004; Nielsen-Bohlman, Panzer, & Kindig, 2004). Yet, there have been no studies of health literacy in the deaf population, despite the obvious risk for lower health literacy arising from lower English literacy and fund-of-information challenges. Some efforts to address this risk have been made, including the development of health education materials for deaf individuals who communicate via ASL (Burgess, Shaw, Larew, Oellette, & Long, n.d.; League for the Hard of Hearing, 1996; Pollard, 2003; Walters, 2004). Such educational materials clearly presume lower health

literacy in the deaf population, judging from the inclusion of health-related content that would be considered common knowledge in the hearing population. Research studies documenting health literacy levels in the deaf population (and the various subpopulations within the broader deaf population) would be helpful in establishing and guiding research, education, medical intervention, and public policy efforts aimed at lowering the risk of health disparities in the deaf population.

A number of health literacy measures have been developed (e.g., Davis et al., 1993; Parker, Baker, Williams & Nurss, 1995; Weiss et al., 2005). One that is commonly used in research studies is the Rapid Estimate of Adult Literacy in Medicine (REALM; Davis et al., 1993). REALM respondents are asked to pronounce 66 English words, compiled from patient education materials and intake forms in primary care settings. The total number of correctly pronounced words is compared with four grade-level normative categories (Davis et al., 1993). Scores lower than "ninth grade and above" are considered indicative of low health literacy (Davis et al., 1993). In research on health literacy disparities, the REALM has proven useful with minority populations whose native language is English (Shea et al., 2004; Wilson, Racine, Tekieli, & Williams, 2003). Only one study has attempted to translate it to another language (Nurss, Baker, Davis, Parker, & Williams, 1995). This Spanish version proved unsuccessful, apparently because of differing phoneme–grapheme parallels in Spanish versus English.

Unfortunately, as presently constructed, the REALM cannot validly be used to assess health literacy in deaf individuals because it is administered as a word-pronunciation task. For individuals with normal hearing, accurate word pronunciation is well correlated with reading comprehension (Wilkinson, 1993). This is not the case with individuals deaf since birth or early childhood, who make up the majority of the ASL-using population (Barnett, 2005). Not only is their word pronunciation ability compromised by general difficulties with speech articulation, but even when reading silently, deaf individuals do not use phonetic decoding strategies to the extent that hearing individuals do (Transler, Leybaert, & Gombert, 1999). Thus, the presumption that correct pronunciation of REALM words predicts comprehension would not extend to deaf ASL users.

Nevertheless, the ability to read and comprehend English words is relevant to health literacy in the deaf population as well as in other U.S. populations in which English literacy is compromised. The vast majority of health information available to the American public is written in English. There is a marked lack of available health information in non-English languages, particularly ASL. Limited ability to read and comprehend English health-related words and phrases is likely associated with lower health literacy and, in turn, risk for health disparities.

In this research study, we sought to explore English health-related vocabulary knowledge in a sample of deaf adults, using a modified version of the REALM task. Rather than administer the REALM as a word-pronunciation task, we altered the REALM instructions to focus on self-reported comprehension of the 66 words and then administered this modified task to a volunteer sample of deaf adults.

Method

Participants

The study took place as part of a larger health screening activity during Deaf Awareness Week in an urban community with a large deaf population. We are fluent in ASL and familiar with the ethical conduct of research with the deaf population (Pollard, 1994, 2002). Sixty-one adults who identified themselves as deaf on a demographic form (*hard-of-hearing* and *hearing* were the other choices) were asked to participate in the study. Of the 61, 4 declined. Of the 57 individuals who participated, 27 were women, 29 were men, and 1 did not specify his or her gender on the demographic form. The participants ranged in age from 21 to 67 ($M = 44.3$, $SD = 12.0$). The majority of respondents (82.4%) reported that the onset of their deafness occurred before age 3. Sign language was the preferred communication mode reported by 77.2% of the participants. The participants were highly educated; 80.8% reported completing a college degree. Only 3.5% of the participants were not high school graduates.

Procedure

The REALM is normally administered using a form that lists 66 health-related vocabulary terms. We designed a form with the same 66 words and a set of instructions at the top. The research purpose of the form was explained to participants, as was the voluntary nature of participation in the study. All 57 participants indicated that they comprehended the instructions (either the written instructions or the instructions we presented in ASL or both) and completed the entire modified REALM instrument. Our only modification was to the original REALM instructions. Rather than requesting word pronunciation, our form instructions read, "Please read these medical words. If you do understand what the word means, circle the word. If you do not understand what the word means, cross out the word." We chose to require participants to provide a specific indication of comprehension or the lack thereof for each of the 66 words rather than allow one of these conditions to be a default. The Flesch-Kincaid grade-level score (Thomas, Hartley, & Kincaid, 1975) for our modified instructions was 2.8.

Results

One point was given for each word a participant circled on the modified REALM, indicating self-reported comprehension of that word. The original REALM also gives respondents 1 point for each word that is correctly pronounced (which is correlated with comprehension for hearing people). The maximum total score possible was 66. Our participants' scores ranged from 8 to 66 ($M = 58.3$, $SD = 12.4$). Table 1 shows the corresponding grade-equivalent levels that would have been associated with our participants' scores if compared with the original REALM's scoring standards and norms. Table 1 also displays these scores in comparison to participants' reported education levels. Table 2 lists the 12 most challenging of the 66 health-related vocabulary terms for our participant sample, both for the entire group and for those with college degrees, as well as the 8 words that all participants reported as understood.

Table 1
Health-Related Vocabulary Task Scores by Education

	Corresponding REALM score range and corresponding REALM grade-equivalent range				
Education	0–18 (below 3rd)	19–44 (4th–6th)	45–60 (7th–8th)	61–66 (9th to high school)	Total
Not indicated	0	0	0	1	1
Grade 12	1	0	1	0	2
High school graduate	1	1	4	2	8
Associate's	1	0	6	6	13
Bachelor's	0	0	2	12	14
Master's	0	0	1	15	16
Doctorate	0	0	0	3	3
Total	3	1	14	39	57

Note. REALM = Rapid Estimate of Adult Literacy in Medicine.

Discussion

Most participants (68.4%) indicated that they understood more than 90% of the REALM terms. Nearly one third of participants (31.6%) earned scores on our modified task that are comparable to the REALM's "below ninth grade" level, which is considered indicative of low health literacy. It is particularly concerning that 29.6% of those with at least a high school education scored in this low range, as did 21.7% of those with college degrees. Given that the order of the 66 REALM terms is considered reflective of increasing difficulty, it is further notable that the words our participants found most challenging were not necessarily those clus-

Table 2
Report of Least and Most Frequently Understood Health-Related Vocabulary Terms for All Participants and Those With College Degrees

Original REALM item no. and word	No. who did not understand (n = 57)	No. with college degree who did not understand (n = 46)
Words least frequently understood		
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
Words understood by all (n = 57)		
3. Pill	0	0
5. Eye	0	0
6. Stress	0	0
9. Germs	0	0
10. Meals	0	0
49. Emergency	0	0
52. Sexually	0	0
53. Alcoholism	0	0

Note. Items ascend in difficulty level from 1 to 66, for native English speakers. REALM = Rapid Estimate of Adult Literacy in Medicine.

tered at the end of the original REALM. These findings suggest that the deaf population is at risk for health consequences associated with low health literacy, regardless of educational attainment, and that unique approaches to addressing health literacy disparities in the deaf population may be warranted because the pattern of word comprehension in this study is different than the pattern manifested on the REALM by hearing individuals.

Our findings of limited knowledge of health-related vocabulary are consistent with prior studies with deaf adults (Lass, Franklin, Bertrand, & Baker, 1978; McEwen & Anton-Culver, 1988). Our study differs in that we used health-related vocabulary commonly used by clinicians and researchers to measure health literacy, our sample was highly educated, and we conducted our study more than a decade after the implementation of the Americans With Disabilities Act of 1990, a law that should have improved access to health-related information.

Our participants indicated which English words from the REALM they did and did not understand. We did not measure actual comprehension of the REALM terms. Some participants may have indicated comprehension of some English terms that they did not correctly understand. We believe this was a more likely error than participants incorrectly indicating that they did not understand an English term. Therefore, our modified REALM instructions may result in an overestimate of actual comprehension.

Our approach to modifying the REALM instructions allowed us to explore the issue of health literacy among a sample of individuals for whom English word pronunciation does not correlate with English reading comprehension. However, our modification of the task makes direct comparison to the original REALM norms tentative. Nevertheless, the results of this study raise concern about health literacy in the deaf population, especially in light of the advanced education of our participant sample. Further research using our REALM modification approach or other appropriate health literacy measures with a larger, less educated deaf participant sample would be valuable, as would similar studies with hearing participant samples who also have limited English proficiency but nevertheless must negotiate health care information in the English language. Validation research comparing self-reported health vocabulary comprehension to other methods of assessing health literacy, in both deaf and hearing populations, is needed. This includes assessing knowledge of English health terms and

their ASL equivalents. To truly assess the health implications, these validation studies would need to correlate knowledge (of health-related concepts and English terms) with actual health outcomes. In the meantime, we believe that accessible health education materials (Pollard, Dean, O'Hearn, & Haynes, 2009) and programs should be developed, implemented, and evaluated to address knowledge gaps and prevent adverse health outcomes with deaf children, adults deaf since birth or early childhood, and their family members.

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