

Research Paper

Bilingual approach to online cancer genetics education for Deaf American Sign Language users produces greater knowledge and confidence than English text only: A randomized study

Christina G.S. Palmer, Ph.D.^{a,b,c,*}, Patrick Boudreault, Ph.D.^d,
Barbara A. Berman, Ph.D.^e, Alicia Wolfson, M.A.^a, Lionel Duarte, B.S.^a,
Vickie L. Venne, M.S.^f, and Janet S. Sinsheimer, Ph.D.^{b,c,g}

^aDepartment of Psychiatry & Biobehavioral Sciences, UCLA, USA

^bDepartment of Human Genetics, UCLA, USA

^cInstitute for Society and Genetics, UCLA, USA

^dGallaudet University, Washington DC, USA

^eDepartment of Health Policy and Management, Fielding School of Public Health, UCLA, USA

^fVeterans Health Administration, UT, USA

^gDepartment of Biomathematics, UCLA, USA

Abstract

Introduction: Deaf American Sign Language-users (ASL) have limited access to cancer genetics information they can readily understand, increasing risk for health disparities. We compared effectiveness of online cancer genetics information presented using a bilingual approach (ASL with English closed captioning) and a monolingual approach (English text).

Hypothesis: Bilingual modality would increase cancer genetics knowledge and confidence to create a family tree; education would interact with modality.

Methods: We used a parallel 2:1 randomized pre-post study design stratified on education. 150 Deaf ASL-users ≥ 18 years old with computer and internet access participated online; 100 (70 high, 30 low education) and 50 (35 high, 15 low education) were randomized to the bilingual and monolingual modalities. Modalities provide virtually identical content on creating a family tree, using the family tree to identify inherited cancer risk factors, understanding how cancer predisposition can be inherited, and the role of genetic counseling and testing for prevention or treatment. 25 true/false items assessed knowledge; a Likert scale item assessed confidence. Data were collected within 2 weeks before and after viewing the information.

Results: Significant interaction of language modality, education, and change in knowledge scores was observed ($p = .01$). High education group increased knowledge regardless of modality (Bilingual: $p < .001$; $d = .56$; Monolingual: $p < .001$; $d = 1.08$). Low education group increased knowledge with bilingual ($p < .001$; $d = .85$), but not monolingual ($p = .79$; $d = .08$) modality. Bilingual modality yielded greater confidence creating a family tree ($p = .03$).

Conclusions: Bilingual approach provides a better opportunity for lower educated Deaf ASL-users to access cancer genetics information than a monolingual approach. © 2016 The Authors. Published by Elsevier Inc. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Keywords: Health disparities; Health education; Genetic counseling; Sign language; Deaf

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* Corresponding author. UCLA Semel Institute, 760 Westwood Plaza, Room 47-422 Los Angeles, CA 90095, USA.

E-mail address: cpalmer@mednet.ucla.edu (C.G.S. Palmer).

Cancer disparities are widening among subpopulations differing by literacy level, race/ethnicity, language, and other characteristics,¹ underscoring the need for culturally and linguistically appropriate cancer health communications. One subpopulation in need of appropriate cancer health communications is the US Deaf community,² for whom American Sign Language (ASL) is the primary language. General information about some cancers exists for this community.^{2–8} However, up to 10% of cancers occur due to a genetic alteration in a high risk gene, which increases the chance of developing cancer and can affect medical management⁹ in ways that could lead to cancer screening^{10–12} and prevention.^{13,14} Access to cancer genetics education is important because it increases genetics knowledge and understanding of factors involved in assessing risk for cancer and possible options.^{15,16} However, no materials exist for Deaf ASL-users on this topic although, in the absence of research, there is no expectation that the prevalence of cancers with a strong genetic component differs between deaf and hearing populations. This study addresses the need for appropriate cancer genetics health-care information for the Deaf community.

Health information in spoken or print English does not satisfactorily address Deaf ASL-users' needs. Language acquisition background for deaf individuals is varied,¹⁷ and as a result, their English reading comprehension level tends to be lower on average^{18,19} than the average 7th–8th grade reading level in the general US population.²⁰ Moreover, most health information is written at even higher grade levels¹ and without attention to cultural aspects of the Deaf community, a particularly important deficit when addressing the sensitive topic of genetics.^{21–24}

Increasing awareness of the need for effective access to health information has led to the development of cancer prevention educational programs for the Deaf community. Though none have addressed genetic predispositions, efforts that address language-concordance by accounting for ASL as the first language for many deaf individuals have been found to increase their knowledge regarding a variety of cancers^{3–8,25,26} and to promote cancer screening behaviors.⁶ Although conveying health information in ASL is key, these efforts also have included visual images and graphics and English language elements such as captioning or English text. These elements take into account the considerable linguistic variation in the Deaf community, ranging from use of ASL to more English-ordered signed form, and that many deaf people routinely communicate using a bilingual approach and visual modality.²⁷ A bilingual approach allows for ASL information provision and inclusion of English medical terminology using text and finger-spelling, which can facilitate understanding and later information recall.^{28–30}

Though a bilingual approach is important, education level has not adequately been taken into account in the design of health information for the Deaf community. This

is a significant oversight because education level, English reading literacy, and ASL proficiency are interrelated,^{19,31,32} suggesting that a more nuanced approach is needed. Since the 2013 American Community Survey^h found that ~50% of the US population with a hearing disability (defined as “person is deaf or has serious difficulty hearing”) aged 21–64 has high school or less education,³³ the absence of education level in tailoring health information may result in a failure to identify and address the health education needs of a significant proportion of this population, likely the Deaf community members at greatest risk for lacking adequate health knowledge.

This randomized study compares the effectiveness of cancer genetics information presented in two modalities, a bilingual ASL with English closed captioning modality and a monolingual English text modality. We hypothesized that ASL-using Deaf adults randomly assigned to the bilingual modality would show greater knowledge gains compared with those randomized to the monolingual modality. We further hypothesized that education level would significantly interact with language modality.

Methods

A parallel 2:1 randomized controlled study design was used, with education as a stratification factor. Before study enrollment began, the statistician prepared a block randomization scheme via excel macro where participant assignments were made within an education level by sampling from a randomly allocated block of size 3 to 15 without replacement. The routine masked block size and upcoming assignments from the study coordinator who implemented it. The statistician was blinded to subject assignment. Low education was defined as high school diploma or less education; high education as some college or more education.

Study sample

Inclusion criteria were: ≥ 18 years, deaf or hard-of-hearing (by self-report), ASL-user, and computer and internet access. Individuals unable to complete an online ASL Grammar Judgment Task-Revised (TGJASL-R, a measure of ASL syntactic competency)^{34,35} within one week were excluded, serving as an additional mechanism to determine if a participant had access to a computer and the internet and was sufficiently computer literate to take part in the study.

Participants were recruited nationally, November 2013–May 2014, via deaf clubs, organizations, community

^h www.disabilitystatistics.org. Click on American Community Survey > Educational Attainment > Disability Type {Hearing Disability} > Education {less than a High School education}. The percentage of this group is 17.6%. Repeat for Education {a high school diploma or equivalent}. The percentage of this group is 32.3%.

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