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AMERICAN SIGN LANGUAGE-ACCESSIBLE DIABETES EDUCATION

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Study Protocol, drafted by the Principal Investigator (PI), Salimah LaForce, and Co-PI, Maureen Linden, hereinafter referred to as "we."

PURPOSE AND AIMS

According to recently published data, 25% of the U.S. population is comprised of adults with disabilities, with approximately 6% of the sample having a hearing disability. Prevalence of hearing disabilities increases with age and poverty level.[i] These estimates are likely conservative due to (a) their limitation to non-institutionalized adults, (b) sampling method, and (c) their reliance on self-identification. People who are culturally Deaf view their deafness as a difference, and thus do not self-identify as having a disability. People who are culturally Deaf view themselves as a linguistic minority, bonded by their use of a common signed language, shared experiences, and shared values and norms (e.g., collectivism, rejection of the disability label, Deaf pride, solidarity, directness, expressiveness).[ii] Like other minority populations in the United States, people who are culturally Deaf are at risk for developing diabetes and acute complications related to unmanaged diabetes. Also, there is a diabetes subtype, maternally inherited diabetes and deafness (MIDD) that, although rare, accounts for a portion of diabetes cases in the deaf population.[iii,iv] Increased risk is associated with low rates of health literacy due to lack of accessible health information[v] and isolation from the hearing world.[vi,vii] Further, because the language and communication barrier for the population is so pervasive, it is anticipated that standard transition of care materials may overestimate the diabetes knowledge of people who are Deaf and transitioning into independent care routines. As such, materials may need to be restructured to account for any knowledge deficits. This project will not only evaluate an educational intervention, but the research is designed in such a way as to measure if there are any between-group differences in knowledge about diabetes based on whether the subject has a diabetes diagnosis or not.

Given the language barrier and insufficent provision of certfied sign lanagueg interpretes during medical vistis, we hypothesize that people who are Deaf without a diabetes diagnosis and those who are Deaf with a diabetes diagnosis will have similar levels of diabetes knowledge.

The aim of this study is to evaluate an ASL-interpreted diabetes educational intervention to quantitatively demonstrate a need for diabetes educational outreach materials to be accessible to people who are Deaf and rely on ASL for clear and effective communications.

SURVEY OF THE FIELD

This project addresses disparate health outcomes related to health literacy levels of people who are Deaf. The Agency for Healthcare Research and Quality (AHRQ) within the U.S. Department of Health and Human Services, notes that low health literacy among all adults in the United States results in adverse healthcare outcomes.[viii] Individuals who are Deaf and hard of hearing have been shown to have lower health literacy levels compared to their hearing counterparts with the same level of formal education.[ix] Dammeyer and Chapman (2017) also found corroborating evidence that people with hearing loss have an increased risk of developing a physical illness compared to the general population.[x] Consequently, the low levels of general health literacy among people who are Deaf increases risk for developing chronic illnesses,[xi,xii,xiii] including diabetes.[xiv] One comparative study found that subjects who were Deaf compared to those who were not had similar rates of diabetes diagnoses when blood sugar levels were tested. However, the subjects that were Deaf had lower levels of awareness about their blood sugar levels, often not self-reporting that they had diabetes when explicitly asked, resulting in poor self-management of their condition.[xv]

Quantifying the prevalence of diabetes among the target population is difficult due to the language barrier and broad health data surveys not consistently accommodating ASL. However, there is evidence that people who are Deaf have a high prevalence of health-related risk factors associated with diabetes. Dair, Ellis, and Lieberman (2006) using body mass index (BMI) national averages for the age group as the comparison found that 23.2% of their sample of children (6-11 years old) who were Deaf were overweight, and 27.2% were at risk for becoming overweight.[xvi] According to the authors, these findings are significant given that being overweight as a child is correlated to adulthood obesity, which in turn is associated with diabetes and other illnesses (e.g., hypertension). Also, there is a diabetes subtype, maternally inherited diabetes and deafness (MIDD) that, although rare, accounts for a portion of diabetes cases in the deaf population.[xvii,xviii]

Barnett et al. (2016; 2017) developed a standardized, computer-based, linguistically adapted public health survey. They asserted that health data from the culturally Deaf are not included in public health surveillance due to the survey instruments not being available in ASL. As such, the specific public health needs of this population are unknown.[xix] This lack of data was posited as a contributing factor to disparate health outcomes because the results of health surveillance studies are used to develop population-specific health outreach, resources, and services. The results of the adapted tool indicated that the sample of Deaf respondents reported higher rates of emergency department use than the general population (16% compared to 6.9% visiting an emergency room twice in one year), as well as a higher propensity to forego utilizing health services due to the costs (22.7% compared to 8.1%).[xx] Extrapolations from these data support the notion that people who are Deaf may present with more acute symptoms and suffer greater health consequences as a result of the confluent factors of delays in treatment and limited health literacy. The research not only provided evidence of disparate health issues experienced by people who are culturally Deaf, but its findings suggest that health disparity outcomes are associated with language barriers, showing a critical need for ASL-adapted health education programs.

As an example of the adverse health impacts of language and communication barriers in the medical context, one could look to research on medication adherence. Many people, for various reasons, struggle with managing their medications and lack of adherence to medication regimens is associated with poorer health outcomes, including 40% of nursing home admissions in people with type 2 diabetes.[xxi] That statistic may be exponentially higher in the population of people who are Deaf. Ferguson and Liu (2015) conducted focus groups with 20 subjects who were Deaf or hard of hearing and found that these subjects struggled with the complexity of the written materials that were given to them as a means of communicating information about their medicines.[xxii] In this study, five of the participants (25%) reported adverse events stemming from a lack of understanding of medication instructions or warnings. These included excessive drowsiness from taking too much medication, dizziness caused by taking two interacting medications together, and needing to pull-over while operating a vehicle under the influence of a prescribed narcotic.[xxiii] In another study, 40% of focus group participants who were Deaf were unaware that an adverse reaction could result from not taking their medications appropriately.[xxiv] Two-thirds (67%) of these respondents stated that they would better understand the information if provided in ASL.[xxv] In sum, while one of the greatest barriers faced by people who are culturally Deaf are communication-based,[xxvi] little has been done to ensure that health education and outreach materials are effectively communicated to the target population.

PROJECT DESIGN

Population: Individuals who are Deaf and who rely on ASL for clear and effective communication/comprehension are the primary target population for this research. Estimates of the size of this population range from 500,000 to 2 million,[xxvii, xxviii] but these estimates are hampered by problems with systemic data collection. Unfortunately, the United States does not document the number of individuals that use ASL as their primary language either through the Decennial Census, the American Community Survey (ACS) or through any government agency. These surveys are administered in written English text, which is not well understood by people who are Deaf and rely on ASL, for whom reading comprehension level has been estimated to be at the fourth-grade level.[xxix, xxx, xxxi] Even if written English is understood by the respondent, the ACS and Decennial Census do not include ASL as an option in their questions regarding household language.[xxxii] Finally, the surveys reflect a hearing primacy evident in the emphasis on spoken language, making it difficult to answer What languages other than English are spoken in the household? if one's native language is ASL.

Screening and inclusion process: Study subjects (n=41) were recruited by project partners, Deaf Link, using ASL-interpreted video recruitment and staffers who are Deaf to communicate with prospective subjects via videophone. Twenty-one subjects were Deaf with a self-reported diabetes diagnosis and 20 subjects were Deaf without a diabetes diagnosis (self-reported).

Inclusion criteria was the provision of informed consent, aged 18 years and older, Deaf whose primary language is ASL with or without a diabetes diagnosis.
Exclusion criteria was minors, people whose primary language is *not* ASL, individuals unable to provide consent due to impaired decision-making.

Intervention: The project produced a video-based ASL interpreted diabetes educational intervention (ASL-ADE). The content for the ASL-ADE intervention was derived from diabetes health information regarding symptoms and risk factors that are published by the American Diabetes Association and subject matter experts Guillermo E. Umpierrez, MD, Professor of Medicine, Emory University School of Medicine, Division of Endocrinology, Metabolism and Chief of Diabetes and Endocrinology, Grady Health Systems; and Ina Flores, MS, RD, CDE, CDN, Assistant Program Director - Emory Latino Diabetes Education Program at Emory University School of Medicine. In collaboration with our subawardee, Deaf Link, Inc., the ASL-ADE scripts were reviewed for content to ensure clarity and determination of ASL signs to be used to convey the meanings. This approach allowed for the collaborative inclusion of Deaf community stakeholder's knowledge, perspectives, and experience related to ASL interpretation of health concepts. Certified ASL interpreters and representatives from the Deaf population met to determine the optimal ASL terms for the content. Based on their expertise, scripts were be refined and revised as necessary. The ASL-ADE video intervention was produced through a multi-step process that consisted of pre-production planning, video production, quality control, and post-production. The final intervention was a four-part video series:

1. What is Type 2 Diabetes?
   https://youtu.be/Nmy84TqxMA8
2. How to Check Your Blood Glucose
   https://youtu.be/QYJyzpzfeoE
3. Understanding Hypoglycemia and Hyperglycemia
   https://youtu.be/wOOWr7Bzd4o
4. Exercise and Nutrition Can Help Manage Diabetes
   https://youtu.be/wWB-xOabb9U

Outcome: All visits were conducted individually though a virtual meeting platform and included a certified ASL interpreter who is bound by professional ethics codes regarding confidentiality. Recruitment and intervention were ongoing from October to December 2020 (rolling enrollment, ~ 30day follow-up). Though the questionnaires are self-report, they were administered by the PI's and the participants' answers directly input into the online Qualtrics survey.

Data was collected using study-specific ASL-interpreted questionnaires designed by project personnel. The questionnaire items that measure diabetes knowledge included in the ASL-ADE intervention were forced choice, closed-ended questions to allow for a total score ranging from 0 correct to all correct. Covariates included self-reported information of interests to the study such as gender, age, educational level, level of pre-study exposure to diabetes-related health information, and health behaviors (e.g., diet, exercise, healthcare maintenance). The content of the post-test (immediate) and post-test 30-day follow-up were identical. The pretest contained demographics questions that we only asked once.

Using a pretest-posttest (immediate), 30-day posttest quasi-experimental design, we tested the effect of the educational intervention on knowledge about diabetes and related health behavior changes. The dichotomous X variable was diagnosis status, and the outcome variable (Y) was test scores. Any observed group mean differences, or lack thereof, were anticipated to be predicted by membership in the group. The pre and posttest intervention questionnaires adapted, in part, from the CDC's *Behavioral Risk Factor Surveillance System* (*BRFSS*) were administered as follows:

Phase One:

Step 1 - Pretests

Section 1: Your Awareness of Diabetes
Section 2: Your Health Behaviors
Section 3: Diabetes Health Literacy
Section 4: Demographics

Step 2 - Research Participants in the intervention Group Views Videos

Step 3 - Posttest Immediate

Section 1: Diabetes Health Literacy

Phase Two:

Posttest ~30 Days Later

Section 1: Diabetes Health Literacy
Section 2: Your Health Behaviors
Debriefing where correct answers are provided for the Diabetes Health Literacy questionnaire and the intervention offered to the control group.

Data handling: The questionnaire based raw data will be electronically stored in the Qualtrics survey platform, using code linkage. A master data file, downloaded from Qualtrics, will be kept as a password protected Excel file to ensure access to unadulterated raw data. Georgia Tech's IT systems continuously monitor for adverse events.

Archiving of data. Data is archived for at least 10 years.

Ethical considerations: this study is conducted in compliance with the ethical principles and guidelines detailed by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research in The Belmont Report, and applicable federal, state, and local laws in Atlanta, Georgia, United States, whichever affords the greater protection to the research subjects. The study procedures and documents were approved by the Georgia Institute of Technology's Internal Review Board, protocol number H19229. A Certificate of Confidentiality was obtained from the National Institutes of Health to help keep subject information confidential. This Certificate provides a way that researchers cannot be forced to disclose identifying information, even by a court subpoena, in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings.

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