Improving Health Literacy in Deaf American Sign Language Users

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Abstract

The Americans with Disabilities Act (ADA) was passed more than 25 years ago in 1990. Despite the ADA legislation, multiple health disparities have been recognized among the second largest group of disabled Americans: the Deaf American Sign Language (ASL) users population. Deaf ASL users continue to experience barriers in accessing health information, accessing health care, and participating in research which limits abilities to achieve ideal health. Increasing health literacy in this population would assist in reducing barriers. Improving health literacy in deaf ASL users involves providing ASL interpreters with proficient health literacy, training health care providers including advanced practice nurses about deaf ASL users, and developing patient health education programs specifically for deaf individuals (i.e.; utilizing native sign language, open captioning, images, and videos).

INTRODUCTION

Healthy People 2020 prioritizes the following goals: achieve health equity, eliminate disparities, and improve the health of all groups. However, the year 2020 is approaching quickly and health disparities still exist. One population who suffers from health disparities is the Deaf American Sign Language (ASL) users.

Issues or "gaps" identified by the literature contribute to health disparities in deaf ASL users; data/ studies regarding deaf ASL users is lacking, deaf ASL users often have low health literacy, and barriers limit health care/ access.² Factors that limit data/ studies include the following: telephone surveys may exclude deaf ASL users and English is a second language for most deaf ASL users which results in low English literacy.² Sparse data/ study availability promotes a lack of health statistics which decreases efforts regarding health improvements and chronic disease prevention programs.² Deaf ASL users are more likely to report more health issues such as obesity, domestic violence, depression, and suicidal behaviors than other adults.² Deaf ASL user adults are also less likely to have preventive screens such as cancer screens.²

Deaf ASL users have limited access to information that is considered common knowledge among individuals

with normal hearing; thus, affecting health literacy. Many deaf ASL users do not know their family history (major information to know regarding risk factors) because he/she may have never heard family history discussed with a primary care provider.² Deaf ASL user adolescents often lack knowledge about cardiovascular disease, family history of cardiovascular disease, and common medical terms such as cholesterol.³

Barriers limit health care for deaf ASL user adults for several reasons. Deaf ASL users are less likely to have seen a physician/health care provider than other adults.² Deaf ASL users are more likely to utilize the emergency department. Deaf ASL users report dissatisfaction with physician-patient communication in primary care, believe there is better access to health care in the emergency department, and are more likely to have public health insurance.⁴ Physicians report that deaf ASL users require more time and effort, interpreter services are not always available, and interpreter services are not reimbursed.² One study revealed that deaf ASL users who saw physicians with full-time ASL interpreter services were more likely to receive preventive care than deaf ASL users who saw physicians elsewhere.²

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INCREASING RESEARCH OPPORTUNITIES WITH DEAF ASL USERS

A paucity of research, studies, and articles exists regarding deaf ASL users' low health literacy. The Cochrane Library contains no reviews regarding low health literacy in the deaf ASL user population. Community-based participatory research (CBPR) is a partnership between researchers and participants that supports collaboration in research efforts. Goals of a CBPR include the following: 1) encourage participants' involvement in research that will directly benefit them; 2) promote sustainable programs that improve health outcomes; and 3) expedite the utilization of findings in participants' communities by creating effective interventions. CBPR would promote reaching out to deaf communities to participate in research which could reduce health barriers and increase health literacy.

IMPROVING HEALTH LITERACY IN THE DEAF ASL USER POPULATION

Health literacy is the ability of individuals to understand basic health information and services needed to make optimal health decisions. People with basic or below basic health literacy skills pay about \$2500 more per year for medications and about \$500 more per year for office appointment than those with above basic health literacy skills. People with low health literacy skills are more likely to be hospitalized, are less likely to complete preventive health exams, and are more likely to experience chronic conditions that are poorly controlled.

One intervention that improves health literacy for deaf ASL users is utilization of an ASL interpreter with proficient health literacy.² Several deaf interpreter organizations advertise providing ASL interpreters with proficient health literacy. Some primary care providers are proficient in ASL and serve larger populations of deaf ASL users than primary care providers who are not proficient in ASL.

Technology has been utilized to enhance opportunities for deaf ASL users to increase health literacy. Several websites include health information presented with sign language, open captioning, images, and videos (Table 1). YouTube has some videos featuring health information that are tailored to the deaf ASL user community. Health information is also available for Spanish speakers and LGBTQIA (Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, Intersex, and Asexual/Agender/Aromantic) individuals who are deaf ASL users.

Table 1

Web Sites with Health Information for Deaf ASL Users and Healthcare Providers

Organization	Website	Information
Deaf Doc National Center for Deaf Health Research (NCDHR)	http://deafdoc.org/	Health information for deaf ASL users and healthcare providers
Deaf Health	http://deafhealth.org/	Health education in ASL
Mano a Mano	https://manoamano-unidos.org/	Trilingual (ASL- English-Spanish) Health Information
National Center for Deaf Health Research (NCDHR)	https://www.urmc.rochester.edu/ncdhr/ information/links.aspx#HealthInformation	Includes listing of websites with health information for deaf ASL users
National Council on Interpreting in Health Care	http://www.ncihc.org/	Information for healthcare providers and interpreters

HEALTH CARE PROVIDER AWARENESS AND EDUCATION

Training for healthcare providers is available online through multiple organizations and includes guidelines, resources, continuing education, and a communication access plan (Table 2). An example of a training opportunity in medical school is Deaf Strong Hospital, a role playing activity created by medical students at University of Rochester's School of Medicine and Dentistry in 1998. Medical students are provided information regarding ASL. They then enter the "Deaf Strong Hospital" where deaf volunteers act as ancillary employees and physicians. ASL is the only communication allowed, and English is not to be used. The medical students present to the Deaf Strong Hospital with a medical issue and are processed through the system and medical appointment. Improving communication challenges between deaf ASL users and healthcare providers is the main objective of the Deaf Strong Hospital.¹⁰

Table 2Learning Opportunities for Health Care Providers

Organization	Website	Information
Community Eye Health Journal	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3678307/	Article outlines interventions in an office to improve communication with Deaf/ ASL users
Hearing Loss Association of America	http://www.hearingloss.org/sites/default/files/docs/ HC_Patient_Complete_Guide.pdf	Communication Access Plan
Joint Commission On Accreditation of Healthcare Organizations (JCAHO)	http://www.jointcommission.org/assets/1/6/EffectiveCommunic ationResourcesforHCOsrevised.pdf	Communication Resources
National Association of the Deaf	https://www.nad.org/about-us/position-statements/position- statement-on-health-care-access-for-deaf-patients/	Communication Guidelines for deaf ASL users
Nursing 2017	http://www.nursingcenter.com/cearticle?an=00152193- 201311000-00009&Journal_ID=54016&Issue_ID=1613962	Continuing Education Units: Improving Communication with deaf ASL users

ADVANCED PRACTICE NURSING INTERVENTIONS

Advanced practice nurses can utilize interventions to improve health literacy in deaf ASL users. Pursuing learning opportunities online reinforces health provider education regarding this topic. Nurse practitioners should encourage deaf ASL users to communicate with family members regarding family history. Nurse practitioners can utilize deaf interpreters with proficient health literacy during appointments. Patient education can be reinforced with websites and YouTube videos that use sign language, open captioning, images, and videos. Deaf ASL users can be encouraged to participate with website development.

Nurse practitioner education should include content as well as clinical opportunities with deaf ASL users. For example, in Arizona the state Commission for the Deaf and Hard of Hearing (http://www.acdhh.org/) is available for classroom visits and is willing to provide lectures for online courses. Arizona State Schools for the Deaf and Blind (https://asdb.az.gov/) offers clinical experiences, consulting, and is willing to provide classroom visits and lectures for online courses. Many states have organizations similar to these that provide similar services and support for advanced nursing education. Collaborating with other colleges or departments may offer opportunities for an interprofessional clinical simulation exercise for students to engage with deaf ASL users.

Advanced practice nurses should consider opportunities to involve deaf ASL users in research studies. CBPR involves collaboration with deaf ASL users. Research studies that utilize ASL interpreters with proficient health literacy to

interview deaf ASL participants or encourage participation in focus groups can be efficacious. Utilization of websites and study interventions that involve sign language, open captioning, images, and videos encourage deaf ASL user participation.

CONCLUSION

Many health care providers do not use ASL interpreters and rely on friends or family with ASL skills, "lip reading", or written communication. However, these interventions are not appropriate. These interventions do not promote communication with deaf ASL users and actually increase barriers to health care for this population. Interventions that improve communication with deaf ASL users have been presented in this article as a means to improve health literacy in deaf ASL users. Advanced practice nurses and other health care providers can utilize these interventions in striving to provide optimal health care and improved health outcomes for the deaf ASL user population.

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Author Information

Angela Brown, DNP, RN, FNP-BC, ANP-BC, CDE

Clinical Assistant Professor, University of Arizona College of Nursing Family Nurse Practitioner, University of Arizona Family and Community Medicine

Arizona, USA