

# Breast Cancer Education for the Deaf Community in American Sign Language

Sean Hickey, MD, Erin L. Merz, MA, Vanessa L. Malcarne, PhD, Darlene Clark Gunsauls, MS, Jessica Huang, PharmD, and Georgia Robins Sadler, BSN, MBA, PhD

The Deaf community (DC) is a subset of the 36–37 million Americans with some degree of hearing loss (Lucas, Schiller, & Benson, 2004; Pleis & Lethbridge-Cejku, 2007). American Sign Language (ASL) is the primary medium of communication for the DC subset (Padden & Humphries, 1990). The exact size of the DC is unknown because federal and state surveys do not list ASL as a language option; however, the DC is estimated to be about 550,000–1,000,000 adults in the United States and Canada (Mitchell, Young, Bachleda, & Karchmer, 2006).

Members of the DC are often “early-deafened,” and develop extensive hearing loss prior to acquiring English fluency (Barnett, 2002); therefore, if English is learned at all, often it will be a second language without the benefit of aural reinforcement. Consequently, the average reading level of the DC is between third and fifth grades (Gallaudet Research Institute, 1996; Holt, Traxler, & Allen, 1997; Singleton, Morgan, DiGello, Wiles, & Rivers, 2004).

Considerable evidence suggests that language and culture barriers qualify the DC as a medically underserved population (Iezzoni, O’Day, Killeen, & Harker, 2004; Steinberg, Barnett, Meador, Wiggins, & Zazove, 2006) and contribute to their poorer health status (Cooper & Powe, 2004). Individuals who are Deaf commonly report difficulties in accessing health care as well as frustrations with doctor-patient communication when health care is received (Barnett & Franks, 2002). Of all of the identified disability subgroups in the United States, the DC reports the highest dissatisfaction with access to and quality of health care (Iezzoni, Davis, Soukup, & O’Day, 2002).

Breast cancer is the most common, as well as the second leading cause of cancer death in women (American Cancer Society [ACS], 2009). Regular screenings detect breast cancer at earlier stages, decreasing morbidity and mortality. A review of the literature disclosed few studies related to women who are Deaf accessing breast cancer information, screening, and treatment (Orsi, Margellos-

**Purpose/Objectives:** To create and evaluate an educational video designed to increase breast cancer-related knowledge and screening behaviors among women who are deaf and use American Sign Language (ASL) as their preferred communication method.

**Design:** A test-retest survey was used to determine retained knowledge following an intervention with an ASL breast cancer education video.

**Setting:** Deaf-friendly community settings in southern California.

**Sample:** 122 women who were deaf with a preference for communicating via ASL.

**Methods:** Participants completed a knowledge survey to determine their breast cancer screening practices and baseline breast cancer awareness. Participants then viewed a 30-minute video in ASL. Immediately after viewing the video, participants completed an identical knowledge survey. The survey was administered again two months after the initial intervention to determine long-term breast cancer knowledge retention.

**Main Research Variables:** Age, breast cancer knowledge and screening practices, education, and health insurance.

**Findings:** At baseline, breast cancer knowledge varied widely and respondents’ answered an average of 3 out of 10 questions correctly. Postintervention, respondents answered an average of 8 out of 10 questions correctly, a significant increase from the baseline scores. At the two-month follow-up, respondents answered an average of 6 out of 10 questions correctly, still a significant increase from the baseline scores.

**Conclusions:** Breast cancer knowledge of women who are deaf increased significantly by viewing an educational video in ASL and most of the new knowledge remained at the two-month follow-up.

**Implications for Nursing:** Nurses can help improve the Deaf community’s (DC’s) access to breast cancer-related information by disseminating awareness of this online program.

**Knowledge Translation:** With this online resource, nurses can more easily initiate discussions to help improve knowledge and screening behaviors in a linguistically and culturally appropriate manner. Improving the DC’s access to breast cancer information is of paramount importance to reducing breast cancer morbidity and mortality in the DC.