

Breast Cancer Education for the Deaf Community in American Sign Language

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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.

Anast, Perlman, Giloth, & Whitman, 2007; Sadler, Gunsauls, et al., 2001; Steinberg, Wiggins, Barmada, & Sullivan, 2002; Wollin & Elder, 2003; Zazove, Meador, Reed, Sen, & Gorenflo, 2009). The Health Belief Model (Janz & Becker, 1984) is used as the foundation for many public health-promotion interventions and recognizes that access to knowledge is an essential step in the process of motivating people to adopt lifestyle changes believed to improve health. According to the model, a person must first know that a problem exists, then have a personalized concern related to the problem, and conclude that the benefits of the strategy recommended for addressing the problem outweigh the negatives associated with making the recommended changes. Therefore, access to education improves overall health by facilitating informed decision making while allowing an individual to become his or her own healthcare advocate.

The current article describes the creation and evaluation of an education video designed to increase access to breast cancer-related knowledge for women who are Deaf. Four hypotheses were tested: (a) At baseline, reported self-perception of the adequacy of the baseline breast cancer knowledge of women who are Deaf would correlate positively with their actual knowledge; (b) at baseline, breast cancer knowledge would be positively associated with baseline breast cancer screening practices (for women aged 40 years or older), age, education, and health insurance; (c) a significant increase in overall breast cancer knowledge would occur immediately postintervention; and (d) gains in knowledge from baseline to postintervention would be retained at the two-month follow-up.

Methods

All elements of the current study received institutional review board approval from the University of California, San Diego (UCSD). All printed documents and communications during participants' involvement were offered in English and ASL.

Development of the Breast Cancer Education Video

Researchers from UCSD in conjunction with a community partner, Deaf Community Services of San Diego, created a pilot breast cancer education program giving the DC access to the information needed for making informed healthcare decisions. Following a review of existing evidence-based education programs, the final script was pilot-tested throughout San Diego County with women who are Deaf, followed by a focused discussion with participants identifying ways to improve the program. The 30-minute video described breast cancer risk factors, screening options, and treatment choices including clinical trials, and delivered the information in a

culturally and linguistically appropriate manner (Sadler, Gunsauls, et al., 2001; Sadler, Huang, et al., 2001). The script was produced in ASL following recommended protocol for audiences who are Deaf. Because members of the DC have varying levels of English literacy, it was deemed culturally appropriate to include open captioning on the video as a complementary way of accessing the information. A voice-over interpretation of an English translation of the ASL script also was added. Background ambient music was excluded intentionally to assure the optimal clarity of the voice over for listeners who are hard of hearing. Generous use of pictorial explanations and summary graphics helped clarify and reinforce the content.

For the video, the 2002–2009 guidelines from the ACS and National Cancer Institute (NCI) were used: (a) yearly mammograms beginning at age 40 years; (b) clinical breast examinations (CBEs) every three years for women aged 20–50 and annually thereafter; and (c) breast self-examinations (BSEs) every month beginning at age 20. The women also were told that they should know how their breasts normally feel and report any breast changes promptly to their healthcare providers (NCI, 2013a; Thomas et al., 2002)

Participant Recruitment

Eligibility criteria included women who were Deaf with a preference for communicating via ASL, aged 18 years or older, and residents of southern California. Participant recruitment strategies included person-to-person dissemination, posting, and viral e-mailing of the project's flyer. Prospective participants were told that they would help to evaluate a health education program offered in ASL and light refreshments would be provided. Individuals who indicated an interest in participating were taken through the formal consent process.

Data Collection

To assess the program's capacity to increase immediate and long-term breast cancer knowledge, the research team identified content on the video considered highly important for cancer control. Then, that content was converted to a 10-item knowledge survey composed of close-ended questions and true or false statements. The survey was reviewed for accuracy by medical professionals, reviewed for clarity by students, and further honed by a focus group of DC members and ASL translators to ensure the cultural and linguistic competency of the refined survey. The pretest included open- and close-ended questions about participants' sociodemographics, communication preferences, and breast cancer screening practices. Immediately after viewing and before any discussion of the ASL breast cancer video, all participants completed the same 10 breast cancer knowledge

questions. Two months after the intervention, participants answered the same questions again. To reduce potential baseline worry, participants were assured that the research team was evaluating the video's capacity to increase participants' knowledge on a health topic and that the baseline survey included questions they were not expected to answer correctly. Therefore, participants were asked not to guess if they did not know an answer. Each answer was scored correct or incorrect with absent responses coded incorrect. At baseline, participants also were asked to report how much they thought they knew about breast cancer on a four-point scale from 1 (no information) to 4 (a lot of information), so that their perceptions could be compared to their actual knowledge scores.

Sample Characteristics

Participants ranged from 18–89 years of age. In general, the sample was well-educated and either insured or able to pay for their health services out-of-pocket. Of the women who were aged 40 years or older ($n = 75$), fewer than half adhered to the screening guidelines set by the NCI, consisting of a yearly CBE and mammogram. Although the majority of participants reported that their preferred mode of communication was ASL or a combination of ASL and lip reading, only a small portion of respondents reported communicating with their doctor in this way. The most commonly reported methods of patient-doctor communication were lip reading, writing notes, and communication via an interpreter. Additional characteristics are presented in Table 1.

Data Analysis

Pearson-Product Moment Correlation was used to assess the simple bivariate relationship between perceived and actual breast cancer knowledge at baseline. Simple associations among individual demographic characteristics and breast cancer knowledge at baseline were assessed using Pearson-Product Moment Correlation (age, education) and point-biserial correlation (insurance status). Paired t tests were used to determine whether overall breast cancer knowledge improved from baseline to the postintervention points of data collection. McNemar's (1947) chi-square change tests were used to determine whether item-level breast cancer knowledge improved from baseline to the postintervention points of data collection.

Results

Baseline Associations

Perceived and actual breast cancer knowledge: At baseline, participants indicated their amount of perceived breast cancer knowledge. Of the 119 respondents who

Table 1. Sample Characteristics (N = 122)

Characteristic	\bar{X}	SD
Age (years)	45.32	14.19
Characteristic	n	%
Ethnicity		
Caucasian	63	52
Hispanic	28	23
African American	9	7
Asian American	8	7
Native American or Alaskan	4	3
Other	6	5
No answer	4	3
Education		
Less than a high school degree	13	12
High school degree	45	37
Some college	23	19
College degree	18	15
Beyond college	13	11
No answer	10	8
Insurance		
Adequate or can pay out-of-pocket	85	70
None	37	30
BCS practices among women older than 40 years of age (N = 75)		
CBE in past 12 months	32	43
Mammogram in past 12 months	21	28
Neither	22	29
Most frequent mode of communication^a		
ASL	59	48
ASL and lip reading	46	38
Lip reading	21	17
Interpreter	20	16
Writing notes	20	16
Other	12	10
Most comfortable mode of communication^a		
ASL	58	48
ASL and lip reading	41	34
Lip reading	10	8
Interpreter	21	17
Writing notes	15	12
Other	9	7
Mode of communication with doctors^a		
ASL	7	6
ASL and lip reading	5	4
Lip reading	36	30
Interpreter	59	48
Writing notes	40	33
Other	18	15

^a Respondents could choose more than one answer.

ASL—American Sign Language; BCS—breast cancer screening; CBE—clinical breast examination

Note. Because of rounding, not all percentages total 100.

answered this item, 25 (21%) indicated that they had no information, 33 (28%) indicated that they had a little information, 38 (32%) indicated that they had a fair amount of information, and 23 (19%) indicated that they had a lot of information. A significant but modest correlation

existed between perceived and actual breast cancer knowledge at baseline ($r = 0.271$, $p = 0.003$), which indicated that respondents who perceived themselves more informed about breast cancer also answered more items correctly on the breast cancer knowledge questionnaire.

At baseline, breast cancer knowledge among respondents varied widely. "At what age should women begin to do BSE?" and "At what age should women begin to have a doctor or nurse do a breast examination every year?" had the fewest correct responses (18 and 20, respectively). Conversely, "True or false: If I have a mammogram, I don't need to do BSE." and "How does a mammogram work?" had the most correct responses (104 and 88, respectively). At baseline, respondents answered an average of 3 out of 10 questions correctly (see Table 2).

Breast cancer knowledge and breast cancer screening practices, age, education, and health insurance: Women aged 40 years or older who were adherent to NCI's CBE screening recommendations (NCI, 2013b) had greater baseline breast cancer knowledge ($\bar{X} = 4.41$) compared to those who were not adherent ($\bar{X} = 3.19$), $t[73] = -2.93$, $p = 0.005$). For the mammogram recommendations, the difference in knowledge scores for adherent ($\bar{X} = 4.33$) and nonadherent ($\bar{X} = 3.46$) women approached significance ($t[73] = -1.84$, $p = 0.07$). Age was not significantly associated with breast cancer knowledge at baseline ($p > 0.05$). However, education was significantly associated with breast cancer knowledge at baseline ($r = 0.37$, $p < 0.001$), in that more educated women answered more items correctly. Insurance status also was significantly associated with breast cancer knowledge at baseline ($r = -0.253$, $p = 0.005$) in that individuals who had insurance answered more items correctly.

Postintervention

The current study tested the hypothesis that providing breast cancer information in ASL via the educational video would facilitate the acquisition of information. Immediately following the educational intervention, knowledge significantly increased on all items except for, "True or false: If

I have a mammogram, I don't need to do BSE." However, the majority of respondents (85%) answered that item correctly at baseline, restricting the possibility of a statistically significant increase in knowledge. At postintervention, respondents answered an average of 8 out of 10 questions correctly, a significant increase from the baseline scores ($t[121] = -17.461$, $p < 0.001$).

Two-Month Follow-Up

Although a slight but nonsignificant decline in correct answers occurred for the majority of questions

Table 2. Knowledge Survey Results (N = 122)

Total Score	Baseline		Post-Intervention		Two-Month Follow-Up	
	\bar{X}	SD	\bar{X}	SD	\bar{X}	SD
Cumulative knowledge score ^a	3.49	1.88	7.58	2.27**	5.53	2.35**
Knowledge Survey ^b	Correct Answers					
	Baseline		Post-Intervention		Two-Month Follow-Up	
How does a mammogram work?	88		104*		104*	
True or false: If I have a mammogram, I don't need to do BSE.	104		107		110	
If 100 women have their breast cancer detected early, about how many do you think will be alive in twenty years?	35		99**		66**	
If 100 women have their breast cancer detected late (after it has spread to other parts of their body) how many women do you think will be alive in twenty years?	31		87**		58**	
At what age should women begin to do BSE?	18		99**		49**	
How often should perform BSE?	46		88**		75**	
At what age should women begin to have a doctor or nurse do a breast exam every three years?	20		95**		48**	
At what age should women begin to have a doctor or nurse do a breast examination every year?	20		72**		51**	
At what age should a woman begin to have mammogram every 1–2 years?	41		88**		61*	
Age that woman should begin to have annual mammogram?	23		86**		53**	

* $p \leq 0.01$; ** $p < 0.001$
^a Paired samples t test
^b McNemar chi-square
 BSE—breast self-examination

from the postintervention to the two-month follow-up, knowledge levels for most items remained significantly increased compared to baseline. At the two-month follow-up, respondents answered an average of 6 out of 10 questions correctly, a significant increase from the baseline scores ($t [121] = -9.532, p < 0.001$). In addition, the long-term knowledge gain was achieved with only a single viewing of the video, which presented complex content that was unlikely to be mastered with only a single viewing.

Discussion

Participants in previous studies reported that cancer information was highly desired by members of the DC (Glicken, 1994; Jones, Renger, & Firestone, 2005; Sadler, Huang, et al., 2001). The present study showed that overall breast cancer knowledge at baseline varied widely among DC participants. About half of the participants believed they had little or no information with respect to breast cancer, which was confirmed by their scores on the breast cancer knowledge test at baseline. The current researchers' review of available breast cancer education materials found few healthcare resources accessible in ASL, a significant barrier to the DC's access to breast cancer information. The current study demonstrated that the breast cancer knowledge of women who are Deaf could be increased significantly by viewing an educational video in ASL and that most of the new knowledge remained at the two-month follow-up.

The Health Belief Model recognizes that knowledge about a health problem is a key component in the process of health-related decision making. Therefore, the DC's access to breast cancer control information must be equal to mainstream access. The breast cancer education video in ASL increased the current participants' correct answers immediately after viewing and the participants retained much of the information at the two-month follow-up. Therefore, data indicate that the breast cancer video intervention in ASL is likely a valuable educational tool for members of the DC.

In light of the depth and breadth of the video, repeat viewings are warranted for the DC to achieve access to breast cancer information equivalent to women who hear. The video was uploaded to the Internet, where it can be viewed repeatedly and in specific parts.

The video has received strong endorsement from established leaders of the DC for its cultural competency, as well as their enthusiastic help with its widespread dissemination. The National Association for the Deaf's free lending library reviewed the video and now distributes it nationally free-of-charge. In addition, 252 deaf-friendly ministries around the United States agreed to receive and show the video to their constituents. It also is available to purchase. The video has received top awards

from international, professionally-juried video competitions where it was submitted to vet its aesthetic and professional qualities. It won a Gold Winner in the 2009 Marcom Awards, as well as a Gold Winner in the 2009 Ava Awards for Informational Content and Medical/Patient Education.

Limitations

Limitations of the current study include a relatively small sample size consisting only of southern California residents. Therefore, the cohort may not accurately represent a cross-section of the DC throughout the United States. Although the items for the knowledge questionnaire were developed by the research team to provide representative coverage of content in the video (with a focus on content validity), the reliability and validity of the items were not tested. The current study also lacked a control group of participants who were Deaf and received an equal, but different, intervention. It also did not include a comparison baseline group of hearing participants.

Future studies should explore those issues, as well as whether the increased access to breast cancer knowledge translates into greater adherence to nationally recommended screening guidelines. Although data were collected to measure current screening practices, it was beyond the scope of the current study to evaluate whether the video could prompt long-term changes in actual screening behavior. Given the evidence that this video positively impacts breast cancer knowledge, the next step would be to evaluate whether those changes in knowledge result in an increase in screening practices. It also would be interesting to compare the baseline knowledge of hearing women and women who are Deaf to evaluate whether significant baseline differences exist between the two groups and the impact of viewing the video. Future studies also could evaluate the impact of repeated video viewings on knowledge gains and retention. Development of a comprehensive video-based review of treatment options in ASL was undertaken by colleagues at University of California, Los Angeles, in collaboration with the Greater Los Angeles Agency for the Deaf and the senior author of this study.

Implications for Nursing

Adherence to breast cancer screening guidelines has been proven to reduce the disease's morbidity and mortality rates. Improving the DC's access to such information is crucial to empower its members to make well-informed, health-promoting decisions. In addition, with the availability of inexpensive, high-quality video cameras and increasingly user-friendly video editing software, nurses in all disciplines can partner with their local DC service organizations to help create an expanding array of health-related videos in ASL. The breast cancer

education video discussed in the current article and others created by the research team are accessible online (<http://cancer.ucsd.edu/coping/resources-education/deaf-info/Pages/default.aspx>) so that nurses may share them with their patients who are Deaf.

Conclusion

The education video in ASL significantly increased the breast cancer knowledge of women who are Deaf. Now accessible to all women who are Deaf, the video offers an effective strategy for addressing the disparities in the dissemination of breast cancer control information that could subsequently culminate in the creation of health disparities if not addressed.

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