Published in final edited form as:

J Cancer Educ. 2009 ; 24(1): 10–15. doi:10.1080/08858190802665245.

The Impact of Cervical Cancer Education for Deaf Women Using a Video Educational Tool Employing American Sign Language, Open Captioning, and Graphics

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Abstract

Background—Deaf women encounter barriers to accessing cancer information. In this study, we evaluated whether deaf women's knowledge could be increased by viewing a graphically enriched, American Sign Language (ASL) cervical cancer education video.

Methods—A blind, randomized trial evaluated knowledge gain and retention. Deaf women (n = 130) completed questionnaires before, after, and 2 months after viewing the video.

Results—With only a single viewing of the in-depth video, the experimental group gained and retained significantly more cancer knowledge than the control group.

Conclusions—Giving deaf women access to the ASL cervical cancer education video (<http://cancer.ucsd.edu/deafinfo>) significantly increased their knowledge of cervical cancer.

In a recent study of deaf¹ women who use American Sign Language (ASL) as their preferred mode of communication, cancer was ranked highly as a health topic for which they needed information.² Unfortunately, direct and suitable communications between deaf patients and health care providers are difficult because most health professionals are unable to communicate in ASL.^{3–8} The Americans with Disabilities Act specifies that health care providers are responsible for providing “reasonable accommodation” to ensure that their deaf patients can access health services.⁹ ASL interpreters and ASL proficient medical personnel can help bridge language barriers and make health visits positive experiences, encouraging patients to discuss intimate health topics.¹⁰ Unfortunately, some physicians minimize the use of interpreters due to shrinking health care reimbursements or are unaware of their legal obligations to provide interpretive services.^{11–15}

Within the Deaf community, the average reading level is third to fifth grade because English is learned as a second language, if learned at all.^{16–20} The absence of aural language reinforcement compounds the difficulty of vocabulary acquisition.²¹ As with other groups who learn English as a second language, the Deaf community faces literacy barriers to accessing health information and services.^{18,19,22} Thus, providers cannot rely solely on printed materials, note writing, captioned programming, or online sources of health information as a means to increase their deaf patients' health knowledge.^{7,22}

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In a previous study with deaf women, more than a third (37%) reported that they personally possessed “no knowledge” of cervical cancer.¹² Lack of knowledge often correlates with reduced screening rates and later detection, placing deaf women at higher risk of late stage disease.²³⁻²⁵ This is especially tragic because cervical cancer is 1 of the most easily and inexpensively controlled cancers.²⁶⁻²⁸ Just 1 screening has been shown to reduce lifetime risk of dying of cervical cancer by 25% to 36%.²⁷⁻²⁹

A cervical cancer education video in ASL with open captioning and voice overlay was produced to give the Deaf community greater access to cervical cancer information. In this article, we present the outcomes of the randomized educational trial done to test a culturally and linguistically appropriate method of increasing access to cervical cancer knowledge among deaf women.³⁰⁻³⁴

Materials and Methods

Hypothesis 1: Women who view a culturally aligned, graphically enriched cervical cancer education video in ASL with open captioning and voice overlay will demonstrate significantly ($P < .05$) more knowledge about cervical cancer than women who do not.

Hypothesis 2: At least 10% of the women who participate in the cervical cancer education group will report reviewing and/or sharing with others the copy of the ASL cervical cancer educational video they receive after the training program.

Development of the Educational Intervention

Community-specific health educational programs are most effective when cultural and linguistic constructs are incorporated.^{31,32,35} The educational partnership (Moore's University of California, San Diego (UCSD) Cancer Center, Deaf Community Services of San Diego Inc., Bovee Productions, the National Association for the Deaf, and Gallaudet University) worked closely with Deaf community agencies and their members throughout Southern California. Through consensus building, a 46-minute, graphically enriched video (*Cervical Cancer: Catch It Early and Save Your Life*) was created that features native ASL signers explaining how cervical cancer develops, who is at risk, how it can be diagnosed and treated, and the importance of clinical trials participation.

Study Design

The UCSD Institutional Review Board approved this blind, randomized controlled trial in which adult, deaf women from Southern California who used ASL as their preferred mode of communication were invited to participate in “a health education study.” After completing the consenting process in English or ASL, all participants completed a baseline (Survey A). They were then randomized to the experimental or control groups. Participants in the experimental arm viewed the ASL cervical cancer education video, whereas the control arm participants received the National Cancer Institute's clinical trials PowerPoint education program: “The Basics.” All educational sessions were conducted by trained, native ASL signers. After the interventions, participants in both groups completed the posttest (Survey B). The experimental group participants received copies of the video “to review and share with friends and loved ones.” They were asked 2 months later to complete Survey C, and participants in the control arm were invited to cross over into the experimental group (see cross-over study design, Figure 1).

All 3 surveys included 13 identical cancer knowledge questions (Table 1). Survey A also contained additional questions about socioeconomic status, and Survey C contained additional questions related to whether they had viewed or shared the video with others. For the control group participants who crossed over into the experimental group, Survey C

served as a second baseline, allowing analysis to determine whether there was a baseline shift. Participants received a complimentary meal during the educational session, and those who completed the Survey C also received \$25.

Data Analysis

The data were double entered into an SPSS database and analyzed using SPSS version 14.0 (SPSS Inc., Chicago, IL). Repeated measures analyses of variance (ANOVAs) were run to test for overall knowledge of cervical cancer, general cancer knowledge, and total cancer score differences over time. ANOVAs were run to test for overall knowledge of cervical cancer differences between groups. Chi-square tests were also run to test for subgroup differences in specific cancer knowledge questions. It was anticipated that the control group members who crossed over into the experimental arm might have a baseline shift in some unforeseen way. Therefore, the data analysis was conducted in 3 ways: with the original members of the experimental arm, with the members of the combined experimental group including women who crossed over, and with the cross-over members only. The results reported are for the combined experimental group unless the analysis disclosed a significant difference.

Sample Description

At baseline, 130 women enrolled: 72 in the experimental group and 58 in the control group, of whom 56 opted to cross over into the experimental group, for a total of 128 in the combined experimental group. The participants' ages ranged from 19 to 93 years (mean age = 41.23, SD = 16.20). Among these women, 1.6% never completed high school, 36.2% completed high school, 28.6% completed some college, 18.4% completed college, and 15.1% completed more than college. Of the sample, 58.4% were Caucasian, 15.7% Hispanic, 9.2% Asian/Pacific Islander, 5.9% African American, 4.3% mixed, and 6.5% other. Analysis of the demographic information between experimental and control groups prior to employing the cross-over model revealed no differences in age, ethnic make-up, education levels, or baseline knowledge ($P = .05$). The retention rate from Survey A to Survey B was 100% and to Survey C was 90.7% (118/130), with dropouts analyzed as "intention to treat."

Results

Hypothesis 1 was proven true. The intervention group demonstrated increased cervical cancer knowledge that was retained at 2 months, whereas the control arm did not show any improvement (Table 2).

To identify the specific areas of knowledge gain, each of the 13 cancer knowledge questions was examined (Table 1). There were no significant differences between the control group and experimental group at baseline for each question. After the intervention, the experimental group's knowledge increased significantly for 5 of the questions and trended upward for all but 1 of the remaining questions. Question 2 asked "Which cancer occurs most often in women?" Fewer women in the experimental group gave the correct answer in Survey B compared to the control group. This shift was primarily due to women in the experimental group shifting from the correct answer of breast cancer to cervical cancer. Of the women in the experimental arm who answered correctly in Survey A, 21 changed their answer to cervical cancer by Survey B in contrast to 3 women in the control group who made this switch, a trend also observed in Survey C.

The 13 knowledge questions addressed 2 main themes: 5 were specific to cervical cancer and 8 related to cancer in general. An analysis was done to determine whether there was a

disproportionate knowledge gain related to cervical cancer. The control group showed no change over time regarding these categories. Whereas both categories of knowledge were equivalent at baseline for the experimental group, participants' cervical cancer knowledge improved significantly more than their general cancer knowledge at Survey B and Survey C. General cancer knowledge increased mildly immediately postintervention and then returned to baseline levels at Survey C (Figure 2).

Hypothesis 2 was also proven true, with 40.2% of the women who received the video saying they either viewed it again themselves or shared it with others compared to the 10% originally hypothesized. When participants were asked "How many times did you view the tape?," 115 answered this question, with 44 participants saying they had viewed it again. Among these repeat viewers, 52.2% said they viewed the video more than once, 43.2% viewed it only once, and the remaining 4.5% did not respond to that component of the question. Survey C also asked "Did you show the video to anyone else?" Of the 115 women who responded, 23.9% said they shared the video with others. The last question asked, "If you did not show the video to anyone else, please tell us why." Lack of time was cited by 42.2%, 18.1% planned to share it with others in near future, 19.3% indicated that they did not have the necessary equipment, and 20.5% gave various other reasons.

Discussion

In spite of the ease of early detection and treatment, 33% of women diagnosed with cervical cancer in 2007 are predicted to die from their disease, largely because of late stage diagnosis.²⁹ Increased adherence to screening and treatment guidelines is the key to reducing this mortality rate.³⁶ Deaf women face greater barriers to knowledge and care than mainstream women. The ASL cervical cancer education video tested in this program offers 1 way of helping deaf women reduce their risk of dying from cervical cancer.

Although study participants in previous studies were concerned about the inadequacy of their cervical cancer knowledge, the women in this study demonstrated relatively high baseline scores.¹² This could be due to an increase in knowledge among deaf women since the partnership's previous study 5 years earlier. It could also have been the result of a self-selection bias whereby highly motivated health information seekers were attracted to a reliable source of additional information. However, despite the limited margin for improvement, participants in the experimental group still demonstrated statistically significant postintervention increases in knowledge and retained that knowledge at 2 months.

The frequency with which the participants reported subsequently reviewing or showing others their video copies is encouraging. Retention of the acquired knowledge, demonstrated immediately following the intervention to the 2-month follow-up, suggests that the women may have indeed been reviewing the videos with this high frequency.

These results are encouraging, signifying that future cancer education efforts in ASL for the Deaf community are warranted and that those available will be well received. Once tested, these videos will be distributed through deaf-friendly ministries nationwide, the National Association of the Deaf's free lending library (Captioned Media Resource), and mounted on a noncommercial, reputable Web site (<http://cancer.ucsd.edu/deafinfo>).³⁷ They will also be available for purchase at the cost of the reproduction and handling fees.

As with other disadvantaged communities, there is a need to provide better access to information and services to the Deaf community regarding cancer prevention and treatment in ways that are comprehensible for its members. This video attempts to accomplish that goal by tapping into the unique aspects of the Deaf culture.

One limitation of this study was that it did not address the cancer screening behaviors of the women, primarily because of the short duration between the intervention and the follow-up for a disease that has screening guidelines of between 1 and 3 years. Another limitation of this study was the single geographic focus from which study participants were drawn. Hence, generalizations must be made with caution.

The Deaf community is considered to be a tightly knit group, a trait that favors the spread of information among its members. This was demonstrated by the relatively high number of women who reported sharing their videos with other women within the comparatively short, 2-month time frame.

Conclusion

This culturally aligned, educational video in ASL was shown to be an effective strategy for increasing and maintaining cervical cancer knowledge among deaf women. The participants also shared the educational materials with others, promoting the dissemination of knowledge throughout their community and among their loved ones.

Acknowledgments

The authors thank the following organizations that made the participant recruitment process possible: Gallaudet University; Deaf Community Services of San Diego, Inc. (DCS) in San Diego; Center on Deafness Inland Empire (CODIE) in Riverside; Orange County Deaf Equal Access Foundation (OC DEAF) in Cypress (Orange County); Deaf program with Disability Support Programs and Services at San Diego Mesa College in San Diego; the National Center on Deafness at California State University Northridge in Northridge; and the Greater Los Angeles Agency on Deafness, Inc. (GLAD).

Supported by The Alliance Healthcare Foundation, the California Endowment, the SIRA Medical-Student Aging Research Training Program; the National Cancer Institute grants R25 CA101317, R25 CA108731, R25 CA65745 and Cancer Center Core grant 5 P30 CA023100-22; the National Institutes of Health's Division of National Center on Minority Health and Health Disparities EXPORT grant P60MD00220; and the Minority Institution/Cancer Center Partnership Program grants U56 CA92079 and U56 CA92081.

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Figure 1.
Crossover study design layout.

Figure 2.

General cancer and cervical cancer knowledge of the experimental group.

Note: $P < .01$ for between-subject analysis as well as repeated measures ANOVA (over time analysis).

Table 1
Survey B Comparison of Each Question Between Experimental and Control Arms

Survey B Questions (Answers)	Percentage of Correct Answers in Control Group [*]	Percentage of Correct Answers in Experimental Group [†]	P
Multiple choice questions			
1. What is cancer? (A disease where there is uncontrolled growth of abnormal cells in the body that can result in death.)	91.4	93.0	.703
2. Which cancer occurs the most often in women? (Breast cancer.)	80.7	62.8 [‡]	.016
3. Which cancer kills the most number of women? (Lung cancer.)	12.1	49.6 [‡]	.000
4. Which of the following is a risk factor for getting cervical cancer? (Having a history of more than 2 sexual partners because it increases your risk of being infected with the human papillomavirus [HPV].)	89.5	97.7 [‡]	.017
5. Which tumor can spread throughout the body and kill a person? (Malignant tumor.)	84.2	95.3 [‡]	.011
True-false questions			
6. Metastasis is a medical term that means cells breaking away from a malignant tumor and spreading to other parts of the body. (True.)	83.9	95.3 [‡]	.009
7. Early detection of a cancer means that you find the tumor before it has already to spread to other parts of the body. (True.)	79.3	85.2	.322
8. Even young women can develop cancer. (True.)	89.7	96.1	.085
9. Every woman should have a pelvic exam and a Pap smear test every year beginning 3 years after having sexual intercourse or no later than age 21. (True.)	49.1	92.9 [‡]	.000
10. Finding cervical cancer early allows most women to have children. (True.)	56.1	87.5 [‡]	.000
11. Human papillomavirus or HPV is the virus that causes most cases of cervical cancer. (True.)	79.2	93.0 [‡]	.007
12. A regular Pap smear is a very good way to find cervical cancer early. (True)	98.3	96.9	.584
13. Clinical trials are studies done to provide more diagnostic and treatment options for cancer and many other diseases. (True.)	94.5	95.3	.826

* n = 58.

[†] n = 128.

[‡] P .05.

Table 2
Demonstration of Increasing Knowledge in the Experimental Group Postintervention

Data Collection Time Points	Scores Out of a Possible Total of 13		
	Control Group [*]	Experimental Group Without Crossover [†]	Combined Experimental Groups [‡]
Survey A: Baseline	9.50	9.40 [§]	9.48 [§]
Survey B: Immediately postintervention	9.67	11.33 [§]	11.34 [§]
Survey C: 2-mo postintervention	9.60	10.38 [§]	10.56 [§]

^{*}n = 58.

[†]n = 72.

[‡]n = 128.

[§]*P* .05 for repeated measures (over time).