

UC San Diego

UC San Diego Previously Published Works

Title

Ovarian Cancer: Deaf and Hearing Women's Knowledge Before and After an Educational Video

Permalink

<https://escholarship.org/uc/item/5pp028jn>

Journal

Journal of Cancer Education, 28(4)

ISSN

0885-8195

Authors

Jensen, Lindsay G

Nakaji, Melanie

Harry, Kadie M

et al.

Publication Date

2013-12-01

DOI

10.1007/s13187-013-0529-2

Peer reviewed

Ovarian Cancer: Deaf and Hearing Women's Knowledge Before and After an Educational Video

Lindsay G. Jensen · Melanie Nakaji · Kadie M. Harry ·
Nick Gallegos · Vanessa L. Malcarne ·
Georgia Robins Sadler

Published online: 24 August 2013
© Springer Science+Business Media New York 2013

Abstract Members of the Deaf community report language and cultural barriers to accessing health information and care. This study evaluated whether an ovarian cancer education video in American Sign Language with English captioning and voice-over could close the anticipated knowledge gap between Deaf and hearing women's cancer knowledge. Consented Deaf ($n=55$) and hearing ($n=52$) women's *General*, *Ovarian*, and *Total Cancer Knowledge* were assessed before and after viewing the video. At baseline, hearing women demonstrated significantly higher *General*, *Ovarian*, and *Total Cancer Knowledge* scores than Deaf women. By the post-test, all of Deaf women's knowledge scores had increased, closing the baseline gap. However, hearing women's post-video knowledge had also increased, thereby creating a new knowledge gap. The ovarian cancer education video offers an effective method to increase ovarian and general cancer knowledge for Deaf and hearing women.

Keywords Ovarian cancer knowledge · Deaf · American Sign Language

L. G. Jensen · N. Gallegos · G. R. Sadler
School of Medicine, University of California, San Diego, 9500
Gilman Dr, La Jolla, CA 92093, USA

L. G. Jensen · M. Nakaji · N. Gallegos · V. L. Malcarne ·
G. R. Sadler (✉)
Moores UCSD Cancer Center, 3855 Health Science Dr, La Jolla,
CA 92093-0850, USA
e-mail: gsadler@ucsd.edu

K. M. Harry · V. L. Malcarne
Department of Psychology, San Diego State University, 5500
Campanile Dr, San Diego, CA 92182, USA

V. L. Malcarne · G. R. Sadler
SDSU/UCSD Joint Doctoral Program in Clinical Psychology, 6363
Alvarado St, Suite 103, San Diego, CA 92120-4913, USA

Introduction

American Sign Language (ASL) is the primary method of communication and a defining criterion for membership in the Deaf community. Although no recent studies have been done to determine the precise number of ASL users in the US [1], a study in the early 1970s [2] found between 250,000 and 500,000 ASL users. That number has likely increased significantly due to population growth and the convincing body of scientific evidence supporting the premise that learning sign language early benefits Deaf children's development [3, 4].

Studies have shown that Deaf individuals experience barriers to accessing medical care, have decreased medical knowledge in comparison to hearing individuals [5–9], and have limited knowledge of cancer prevention and screening [10, 11]. Deaf people report fear, mistrust, frustration, communication barriers, and cultural incompetency among health care providers, as well as other barriers to accessing health care [12]. These findings indicate that the current methods for delivering health care information to the Deaf community are inadequate. Effective ways to close the gap in medical knowledge, improve access to health information and care, and create more positive relationships between the Deaf community and the health care system need to be created. Educational programs in ASL that are presented in a culturally competent manner offer one way of overcoming these barriers [5, 13].

A community–campus partnership (Moores UCSD Cancer Center, Deaf Community Services of San Diego, Inc., Bovee Productions, Gallaudet University, and the National Association of the Deaf) was created to address these problems. One strategy was to create cancer education videos in ASL with open captioning and detailed graphics and then scientifically test the videos' capacity to facilitate the acquisition and retention of cancer knowledge by members of the Deaf community, as well as appropriate behavioral changes. Studies have demonstrated the usefulness of such videos to improve knowledge about prostate [14], testicular [15], colorectal [16], cervical

[17], breast [18], and skin cancer [19]. In contrast, a recent study of an educational video on general cancer prevention found that although Deaf persons' knowledge of cancer prevention information increased with a captioned ASL video, it did not go up significantly more than for Deaf persons who saw the same video without ASL or captions [20].

In an earlier study by this research team, 36 % of Deaf women reported having no knowledge about ovarian cancer [18]. Over 22,000 women are diagnosed with ovarian cancer, and over 14,000 women die annually from ovarian cancer in the US [21]. It is the second most common form of gynecologic cancer and the most deadly [22]. Enhanced access to ovarian cancer information is important to help people better understand this disease. As treatment methods improve, better public understanding of ovarian cancer and its early warning signs may help improve quantity and quality of life.

To increase the Deaf community's access to ovarian cancer information, the research team created *Finding and Surviving Ovarian Cancer*, a video to give the Deaf community better access to that information. This study evaluated the effectiveness of the video by testing the following hypotheses: (1) Deaf women would have significantly lower baseline *General*, *Ovarian*, and *Total Cancer Knowledge* scores than hearing women, (2) both Deaf and hearing women's knowledge would increase from pre- to post-intervention, (3) these knowledge increases would be equivalent across groups, and (4) Deaf women's post-intervention scores would equal or exceed hearing women's baseline scores.

Methods

Development of the Educational Intervention

UCSD's institutional review board approved this study. The community-campus partnership works closely with members of the Deaf community to create culturally aligned and graphically enriched cancer education videos in ASL. The videos include optional open captioning of the ASL script and English voice-over without background music to reduce audio competition with the spoken text, making them more accessible to people who are hearing and hard-of-hearing.

The 35-min script, *Finding and Surviving Ovarian Cancer* video (available at <http://cancer.ucsd.edu/coping/resources-education/deaf-info/Pages/ovarian-cancer.aspx>), features native ASL signers learning from a peer educator. They discuss how ovarian cancer develops, who is at risk, how it can be diagnosed and treated, and the importance of early detection and clinical trials participation.

The video script was written by a medical content expert and honed by a second medical content expert to assure clarity and completeness. The research team, which includes ASL linguistic experts, consultants from Gallaudet University, the

National Association of the Deaf, and a panel of community members from the Deaf community reviewed the script to ensure cultural alignment and the selection of English vocabulary that could be clearly translated into existing ASL vocabulary. In this regard for example, using the word "tissue" presented challenges because it has only a single meaning in ASL—a soft paper. Such terms had to be carefully explained in the video. The script was then forward translated into ASL and back translated into English by a second group. Any discrepancies with the original English script were adjusted, and the script was again forward and back translated until the forward and back translations matched. The ASL translation was then captured in ASL gloss, the closest written approximation of the ASL version of the final signed script. The ASL gloss version of the script was uploaded to the teleprompter for cuing the signers during filming.

The video's participants were members of the Deaf community and known for their clarity of ASL signing, but without professional acting training. They were selected following a series of interviews in front of a video camera to assure that their signing and composure could be maintained during the video's filming.

A professional ASL coach mentored the actors prior to filming to ensure that they were signing the scripts using universal forms of ASL signs and devoid of colloquial and regional signs. The coach monitored the actors' signing during the videotaping to ensure their signing accuracy. During filming, an ASL interpreter voiced the script as it was signed, so that the medical expert could follow along with the script to ensure adherence. Filmed segments were reviewed and refilmed as needed to ensure signing clarity and adherence to the script.

During the post-production phase, the video was edited and back translated by two signers to ensure the integrity with the script and to refine the written script for subsequent inclusion as open captioning and a voice-over recording. The ASL version was next shown to members of the Deaf community who had not previously seen the video to ensure its clarity and cultural and linguistic competency. The professional voice-over recording of the script was added to the final version of the video along with the open captioning. While the Deaf community's preferred mode of communication is ASL, written English is used by members of the community to varying degrees to enhance their understanding of signed information. Hence, including the option of seeing the captioned script is in cultural alignment with the Deaf community. A final review of the video's accuracy was done by having multiple interpreters, and members of the Deaf community independently ensure that the signing, open captioning, and voice-over recording were all clear and synchronized. Finally, to evaluate the professional and esthetic qualities of the final production of the video, it was submitted to international, professionally juried video competitions.

The demonstration study reported in this paper was done to evaluate the video's capacity to evaluate Deaf and hearing women's baseline ovarian cancer knowledge and the impact on their ovarian cancer knowledge produced by a single opportunity to view the video. By including both Deaf and hearing women, it was also possible to compare Deaf and hearing women's baseline knowledge and post-video changes in their ovarian cancer knowledge.

Participants

The ovarian cancer education video used in this study was created in ASL as an educational tool for Deaf women, but the voiceover (without background music) and captions made the video accessible to people who are hearing and hard-of-hearing. In this study, the video's educational impact was tested with a sample goal of 50 Deaf and 50 hearing women who were at least 18 years old. Deaf women were eligible if they self-identified as Deaf and if ASL was their preferred mode of communication, while hearing women were eligible if English was their preferred mode of communication. Since the primary concern in this study was whether women who relied upon ASL would benefit from this educational video, we did not collect data about their level of hearing loss nor how or when women became Deaf (Table 1).

Women were recruited to the study between February 2009 and January 2010. Part of the sample was recruited from San Diego, California. To expand the geographic area in which the video was tested, participants were also recruited among women living in central Wisconsin. Participants were recruited via an IRB-approved flyer and snowball sampling strategies [23]. Flyers were distributed using person-to-person delivery, e-mailed dissemination via various listserves, and

distribution at organizations and events that attracted Deaf and hearing women.

Procedures

All written elements of this study were offered with ASL translations for Deaf participants. Deaf and hearing women were invited to "participate in a health education study." After completing the written consenting process, participants completed a pre-video *Cancer Knowledge Survey*, which was composed of knowledge questions that had previously been pilot tested with Deaf and hearing women. They then viewed the ovarian cancer education video, and immediately after viewing the video, participants completed a survey with the same knowledge questions. The surveys were analyzed using a *Total Cancer Knowledge* score (all 29 items) and two subscale scores as follows: *General Cancer Knowledge* (5 items) and *Ovarian Cancer Knowledge* (24 items) (Questions are in Table 2). The pre-video survey also contained sociodemographic questions, while the post-video survey contained questions related to the participants' opinions about the video.

Data Analysis

When the sample size goal of at least 50 hearing and 50 Deaf women was reached, the data were entered into SPSS software version 17.0 (SPSS Inc, Chicago, IL) for analysis. Baseline knowledge scores were compared between the two groups (hypothesis one), and then the pre- and post-intervention data were evaluated to test hypotheses two through four. *General* and *Ovarian Cancer Knowledge* scores were calculated by summing the correct number of responses for each respective category; *Total Cancer Knowledge* was calculated by summing all correct responses. Higher scores represent greater knowledge. Independent samples *t* tests were conducted to examine pre-test differences in *General*, *Ovarian*, and *Total Cancer Knowledge* scores between the Deaf and hearing groups. All three scores are offered, while noting that the larger number of ovarian versus general cancer questions meant that the ovarian knowledge score would disproportionately influence the *Total Cancer Knowledge* score. Paired samples *t* tests were conducted to examine pre- to post-test differences for *General*, *Ovarian*, and *Total Cancer Knowledge* scores, as well as for individual survey questions. Repeated measures ANOVAs were conducted to determine whether there was an interaction of group (Deaf or hearing) and time-point (pre- or post-intervention). Independent samples *t* tests were conducted to compare Deaf women's post-test to hearing women's pre-test *General*, *Ovarian*, and *Total Cancer Knowledge* scores. Chi-square and Fisher's exact tests were used to compare participants' opinions about the video and sociodemographic characteristics. Fisher's exact tests were completed using R statistical software (www.R-Project.org).

Table 1 Sample characteristics

Characteristic	Deaf	Hearing	<i>P</i> value
Participants	55	52	NA
Mean age, years (SD)	52 (10.4)	60 (8.1)	<0.001
Race			<0.001
Caucasian (%)	41 (74.5)	49 (94.2)	
Hispanic (%)	9 (16.0)	0	
Asian/Pacific islander (%)	2 (3.6)	0	
Other (%)	3 (5.5)	1 (1.9)	
Did not reply (%)	0	2 (3.8)	
Education			0.04
High school (%)	10 (18.2)	11 (19.2)	
Some college (%)	11 (20.0)	11 (19.2)	
Completed college (%)	15 (27.3)	12 (23.1)	
More than college (%)	10 (18.2)	19 (36.5)	
Did not reply (%)	9 (16.0)	1 (1.9)	

Table 2 Pre- and post-test percent correct responses for *Total, General, and Ovarian Cancer Knowledge* by question and hearing status

Survey question (correct answer)		Total correct responses (%)					
		Deaf (<i>n</i> =55)			Hearing (<i>n</i> =52)		
<i>General Cancer Knowledge</i>		Pre	Post	<i>p</i>	Pre	Post	<i>p</i>
1	Cancer is a disease where abnormal cells start to grow and rapidly spread (<i>True</i>)	47 (86 %)	53 (96 %)	<0.05	45 (87 %)	50 (100 %)	<0.05
2	More women die from ovarian cancer than any other cancer (<i>False</i>)	29 (53 %)	38 (69 %)	NS	33 (64 %)	51 (98 %)	<0.001
3	A benign tumor is not cancer (<i>True</i>)	42 (76 %)	45 (82 %)	NS	49 (92 %)	50 (100 %)	<0.05
4	Tumor cells can break away from a malignant tumor and move to other parts of the body (<i>True</i>)	44 (80 %)	53 (96 %)	<0.05	49 (94 %)	50 (100 %)	NS
5	Benign tumors do not usually need to be removed (<i>False</i>)	32 (58 %)	25 (56 %)	NS	33 (64 %)	43 (83 %)	<0.05
Total General (out of 5)		3.5 (70 %)	3.9 (78 %)	<0.05	4.0 (80 %)	4.8 (96 %)	<0.001
<i>Ovarian Cancer Knowledge</i>							
1	Most treatments for ovarian cancer make it possible for women to have children in the future (<i>False</i>)	27 (49 %)	43 (78 %)	<0.05	18 (35 %)	45 (87 %)	<0.001
2	Women who reach menopause before age 50 are more likely to get ovarian cancer (<i>False</i>)	41 (75 %)	31 (56 %)	<0.05	30 (58 %)	38 (73 %)	NS
3	Never having children increases a woman's risk for ovarian cancer (<i>True</i>)	30 (55 %)	50 (91 %)	<0.001	37 (71 %)	49 (94 %)	<0.05
4	Breastfeeding decreases a woman's risk for ovarian cancer. (<i>True</i>)	34 (62 %)	40 (73 %)	NS	37 (71 %)	48 (92 %)	<0.05
5	Loss of appetite can be a symptom of ovarian cancer. (<i>True</i>)	33 (60 %)	52 (95 %)	<0.001	28 (54 %)	50 (100 %)	<0.001
6	Weight gain can be a symptom of ovarian cancer. (<i>True</i>)	18 (33 %)	51 (93 %)	<0.001	34 (65 %)	47 (90 %)	<0.05
7	Ovarian cancer does not cause irregular menstrual periods (<i>False</i>)	38 (69 %)	38 (69 %)	NS	37 (71 %)	42 (81 %)	NS
8	Other medical conditions can cause symptoms similar to ovarian cancer (<i>True</i>)	37 (67 %)	41 (75 %)	NS	51 (98 %)	50 (100 %)	NS
9	There are several good tests to help find ovarian cancer early (<i>False</i>)	10 (18 %)	15 (27 %)	NS	26 (50 %)	38 (73 %)	<0.05
10	CA-125 is a reliable and recommended screening method for ovarian cancer (<i>False</i>)	12 (22 %)	14 (26 %)	NS	12 (23 %)	41 (79 %)	<0.001
11	Beginning at age 21, you should have a pelvic exam once every two years (<i>False</i>)	19 (35 %)	19 (35 %)	NS	14 (27 %)	23 (44 %)	<0.05
12	A vaginal ultrasound is a painful procedure (<i>False</i>)	43 (78 %)	44 (80 %)	NS	51 (98 %)	50 (96 %)	NS
13	A biopsy can remove some cells from the ovary to see if they are cancer cells (<i>True</i>)	50 (92 %)	53 (96 %)	NS	51 (98 %)	50 (100 %)	NS
14	A special way of delivering chemotherapy has been developed for ovarian cancer (<i>True</i>)	34 (62 %)	44 (80 %)	<0.05	32 (62 %)	47 (90 %)	<0.05
15	Ovarian cancer chemotherapy kills only cancer cells (<i>False</i>)	18 (33 %)	24 (44 %)	NS	40 (77 %)	50 (96 %)	<0.05
16	Ovarian cancer chemotherapy can cause hair loss (<i>True</i>)	50 (91 %)	54 (98 %)	NS	46 (89 %)	50 (100 %)	<0.05
17	Most ovarian cancers require radiation therapy (<i>False</i>)	15 (28 %)	35 (64 %)	<0.001	24 (46 %)	48 (92 %)	<0.001
18	Most ovarian cancers occur in women ages 35–50 (<i>False</i>)	23 (42 %)	44 (80 %)	<0.001	26 (50 %)	50 (100 %)	<0.001

Table 2 (continued)

Survey question (correct answer)		Total correct responses (%)					
		Deaf (<i>n</i> =55)			Hearing (<i>n</i> =52)		
<i>General Cancer Knowledge</i>		Pre	Post	<i>p</i>	Pre	Post	<i>p</i>
19	A personal history of breast cancer increases your risk of getting ovarian cancer. (<i>True</i>)	37 (67 %)	49 (89 %)	<0.05	23 (44 %)	51 (98 %)	<0.001
20	Having a mother, sister or daughter with ovarian cancer does not increase your risk of getting ovarian cancer (<i>False</i>)	51 (93 %)	52 (95 %)	NS	46 (89 %)	50 (100 %)	<0.05
21	Using birth control pills can decrease your risk of getting ovarian cancer (<i>True</i>)	12 (22 %)	41 (75 %)	<0.001	14 (27 %)	45 (87 %)	<0.001
22	Symptoms of ovarian cancer vary depending on the size and location of the tumor (<i>True</i>)	46 (84 %)	47 (86 %)	NS	48 (92 %)	40 (77 %)	<0.05
23	A vaginal ultrasound test can tell if an ovarian tumor is cancer (<i>False</i>)	27 (49 %)	18 (33 %)	<0.05	46 (90 %)	41 (79 %)	NS
24	The best way to screen for ovarian cancer is the yearly pelvic exam (<i>True</i>)	50 (91 %)	50 (91 %)	NS	36 (69 %)	50 (100 %)	<0.001
Total Ovarian (out of 24)		13.7 (57 %)	17.3 (72 %)	<0.001	15.5 (65 %)	21.3 (89 %)	<0.001
<i>Total Cancer Knowledge</i> (out of 29)		21.2 (73 %)	<0.001	19.5 (67 %)	26.1 (90 %)	<0.001	

Results

Participant Characteristics

Of the study participants, 55 of the women were Deaf and 52 were hearing. Compared to the hearing women, the Deaf women were, on average, younger ($p<0.001$), more ethnically diverse ($p<0.001$), and reported completing slightly less formal education ($p=0.04$) (see Table 1).

Hypothesis 1 Deaf women will have significantly lower baseline *General*, *Ovarian*, and *Total Cancer Knowledge* scores than hearing women.

For the five-item *General Cancer Knowledge* subscale, there was a significant difference between Deaf ($M=3.5$, $SD=1.1$) and hearing ($M=4.0$, $SD=1.0$) women's baseline scores, $t(105)=2.4$, $p=0.02$. For the 24-item *Ovarian Cancer Knowledge* subscale, there was also a significant difference between Deaf ($M=13.7$, $SD=2.5$) and hearing ($M=15.5$, $SD=2.5$) women's baseline scores, $t(105)=3.7$, $p<0.001$. For the *Total Cancer Knowledge* score, which was the sum of the two subscales with a maximum score of 29, there was a significant difference between Deaf ($M=17.3$, $SD=2.7$) and hearing ($M=19.5$, $SD=$

2.8) women's baseline scores, $t(105)=4.2$, $p<0.001$.

Hypothesis 2 Both Deaf and hearing women's knowledge will increase from pre- to post-intervention.

For the *General Cancer Knowledge* domain, Deaf women significantly increased from pre- to post-test, $t(54)=2.2$, $p=0.034$, as did hearing women, $t(51)=5.8$, $p<0.001$. For *Ovarian Cancer Knowledge*, Deaf women significantly increased from pre- to post-test, $t(54)=8.7$, $p<0.001$, as did hearing women, $t(51)=15.0$, $p<0.001$. For *Total Cancer Knowledge*, Deaf women significantly increased from pre- to post-test, $t(54)=8.1$, $p<0.001$, as did hearing women, $t(51)=15.4$, $p<0.001$.

Hypothesis 3 Knowledge increases will be equivalent for Deaf and hearing women.

For *General Cancer Knowledge*, there was a significant interaction between time-point and hearing status, $F(1, 105)=28.3$, $p<0.001$, indicating that hearing women yielded a greater mean change in knowledge (M difference=0.8) compared to Deaf women (M difference=0.4). For *Ovarian Cancer Knowledge*, there was a significant interaction between time-point and hearing status, $F(1,$

105)=43.3, $p<0.001$, indicating that hearing women yielded a greater mean change in knowledge (M difference=5.8) compared to Deaf women (M difference=3.5). For *Total Cancer Knowledge*, there was a significant interaction between time-point and hearing status $F(1, 105)=51.7$, $p<0.001$, indicating that hearing participants yielded a greater mean change in overall knowledge (M difference=6.6) compared to Deaf women (M difference=3.9). Given their higher baseline knowledge levels and their greater mean change in knowledge, hearing women continued to have significantly higher *General*, *Ovarian*, and *Total Cancer Knowledge* than Deaf women post-intervention ($p<0.001$).

Hypothesis 4 Deaf women's post-intervention scores will equal or exceed hearing women's baseline scores.

The hypothesis that Deaf women's post-intervention scores would equal or exceed hearing women's baseline scores was supported. Deaf women's post-intervention *Ovarian Cancer Knowledge* score ($M=17.3$, $SD=3.5$) was significantly greater than hearing women's pre-intervention *Ovarian Cancer Knowledge* score ($M=15.5$, $SD=2.5$), $t(105)=2.9$, $p=0.004$. Similarly, Deaf women's post-intervention *Total Cancer Knowledge* score ($M=21.2$, $SD=4.1$) was significantly greater than hearing women's pre-intervention *Total Cancer Knowledge* score ($M=19.5$, $SD=2.8$), $t(105)=2.3$, $p=0.021$. For *General Cancer Knowledge*, there was no significant difference between post-intervention Deaf ($M=3.9$, $SD=0.9$) and pre-intervention hearing ($M=4.0$, $SD=1.1$) women's *General Cancer Knowledge*, $t(105)=0.6$, $p=0.555$.

Demonstrated Limitations of the Video

Identifying specific content areas that were less well communicated by the video would be helpful for educators using this video to know. Therefore, the changes in scores on each individual question were explored. Although there was a general pattern of item-level knowledge increases from before to after the intervention for both groups, there were two questions (2 and 23) on the *Ovarian Cancer Knowledge* subscale for which the Deaf participants' scores were statistically significantly worse after watching the video (Table 2).

Subjective Evaluations of the Video

Participants' opinions about the clarity of the video's content and likelihood of sharing their viewing experience with others also provided important assessments of the video's effectiveness. Hearing women found the information on the video to be "very easy" (96 %) or "somewhat easy" (4 %) to understand. The majority of Deaf women also found the video "very easy" (64 %) or "somewhat easy" (28 %) to understand. These differences were statistically significant ($\chi^2=16.9$, $p<0.001$). Among the Deaf women, 6 % found the video "somewhat difficult" and 2 % found the video "very difficult" to understand. The majority of both groups also reported that, if given the video, they would be willing to share it with a friend (Deaf =87.3 %, hearing=84.6 %; $\chi^2=0.013$, $p=0.91$).

The video competed highly favorably in the international, professionally juried video competitions, winning: 1) Honorable Mention in the 2004 MarCom Creative Awards; 2) both a Finalist Winner Award and a Bronze Award in 2005 for the 26th Annual Telly Awards; and 3) an Award of Distinction in the 2005 Communicator Awards.

Discussion

There have been few public health campaigns related to ovarian cancer because there are currently no evidence-based methods for the prevention or early detection of the disease. Thus, it was not surprising that both groups had relatively low knowledge scores on the *Ovarian Cancer Knowledge* subscale at pre-test. However, for the Deaf women in this study, even the limited publicly available information appeared to have been difficult to access, supporting this study's hypothesis that the barriers Deaf women face to accessing health information would result in them possessing less *General Cancer* and *Ovarian Cancer Knowledge* than hearing women. This finding is consistent with previous studies that showed a lower level of cancer knowledge in the Deaf community [17, 18], and is of concern because greater health knowledge usually predicts increased adherence to health promoting behaviors [24, 25].

The finding that Deaf women had increased *General* and *Ovarian Cancer Knowledge* scores following a single viewing of the ASL and English subtitled video is consistent with previous studies of similar video educational ASL interventions on cancer [14–19]. This gives the community an evidence-based tool that can be used by health educators or as a self-paced on demand Internet resource.

While this offers an encouraging strategy for reducing the Deaf community's ovarian cancer knowledge disparities, a recent randomized controlled trial by Zazove et al. [20] suggested that just the act of giving attention to Deaf women's need for information could significantly increase their

knowledge, regardless of the language in which the video's content is delivered. Zazove's study randomized more than 200 Deaf individuals to view a cancer screening video with and without ASL and captions. They found that while knowledge scores did increase after viewing the videos, the increase was not significantly greater in the group that viewed the video in ASL with captions. Consistent with our research team's earlier studies, they also found that knowledge decreased over time, though the scores still remained above the baseline scores [15–17, 19]. Given the additional costs of producing videos in ASL, Zazove's finding is significant and warrants further exploration.

In the present study, Deaf women demonstrated significantly lower baseline knowledge, a significantly lower increase in post-video knowledge after viewing the video, and a significantly lower percentage who considered the video "very easy" to understand. Several factors may have contributed to these disparities and may also be linked to Zazove's findings. For example, the greater demonstrated baseline knowledge that hearing women had about ovarian cancer in this study and cancer in general may have helped them to assimilate, retain, and recall more of the new information that they received in the video.

Research has shown that Deaf people are less likely than hearing people to report receiving preventive medical information from their physician or the media [26]. Furthermore, even when printed medical information is provided to Deaf people, an additional barrier is the relatively advanced grade level required to comprehend most educational health materials, commonly requiring a ninth grade to college reading level [27]. Deaf students who graduated from high school have been found to have an average fourth grade English reading level [28], making this information difficult to access.

Another possible contributing factor may have been that Deaf people begin acquiring their ASL skills at diverse ages and different training formats, resulting in diverse levels of ASL proficiency. Similarly, Deaf women begin acquiring their English language skills at diverse ages and with diverse training formats, resulting in diverse levels of English proficiency. Thus, while it is appropriate to have given Deaf women the option of accessing the information through both modes of communication simultaneously, their training in language was neither mandated nor consistent, which could have contributed to less than equivalent language proficiency compared to hearing women in the study. Hence, this contributed to a portion of the women's reported challenges to accessing the information with ease. The ASL literacy barrier may have been further compounded by ASL's limited medical vocabulary, a circumstance that makes complex medical topics difficult to explain and to grasp clearly in ASL. Collecting additional information about how and when study participants became Deaf, and how and when they learned ASL and English would be helpful in assessing their response to similar educational programs.

Regardless of the cause(s) of this disparity, health educators who use this video with members of the Deaf community should be cognizant of these challenges. They can then test strategies that could resolve them. For example, women could be encouraged to view the video a second or third time. Alternately, the video was intentionally created using a question and answer format so that a health educator facilitating a training session could easily stop the video to encourage discussion, and hence reinforcement of the video's content, which might be one way to circumvent the problem.

An in-depth review of the scientific literature suggests that this study may be the first data reported related to the evaluation of an ovarian cancer education program for Deaf women. At least one previous study of hearing women diagnosed with ovarian cancer found that watching an educational video was effective in increasing participants' knowledge of ovarian cancer, compared to the control arm's video about gardening [29]. A video approach to educating Deaf women is particularly important, as it may be one of their few ASL-accessible sources of information about ovarian cancer. Furthermore, as a self-paced Internet accessible program, members of the Deaf community can view the video on-demand when needed, as often as desired, and can also print the script for reinforcement or discussion with a health care provider.

Study Limitations

Small sample size and limited geographic diversity are recognized limitations of this study. There were significant differences between the ages, educational levels, and ethnicities of the Deaf and hearing study groups. Data were not collected on causes and age of hearing loss, as well as "level" of deafness and use of assisted listening devices, factors that could affect how subjects responded to the video. Another limitation is that 38 % of the Deaf participants reported previous involvement in a cancer-related education program (although not on ovarian cancer) through the educational partnership's ongoing efforts to make cancer information more accessible to the Deaf community. With more than one third of the women reporting prior involvement in cancer related research studies, it is possible that this Deaf community sample has above-average access to cancer information compared to the US Deaf community at large. Therefore, the demonstrated baseline cancer knowledge disparities between Deaf and hearing women seen in this study may actually be an underestimate of the nationwide disparity and, hence, demonstrates the even greater need for improved access to health education programs in ASL. More than 50 % of the Deaf population in this study had gone to college, which is not representative of the US Deaf community at large [30], suggesting that Deaf women with lower levels of education may experience even greater knowledge disparities and may have more difficulty with the

information in the video. Finally, due to the lack of funding for this specific focus on the evaluation of the video, subjects in this study were not followed over several months to assess knowledge retention. Future studies could consider evaluating the Deaf and hearing women's longer-term retention of their ovarian cancer knowledge gains.

Future Research

Since hearing women gained further knowledge after viewing the video, it would be helpful to assess whether giving Deaf women the opportunity to view the video a second time would enable them to reach the post-viewing knowledge gains achieved by the hearing women.

Conclusion

This study suggests that with increased access to ovarian cancer education, as well as general cancer education, Deaf women's ovarian cancer knowledge can equal or exceed hearing women's baseline knowledge. However, because hearing women's knowledge also increased significantly after viewing the video, further study is warranted to see if this gap can be closed by offering Deaf women additional opportunities to view the video.

Acknowledgments The authors acknowledge the following sources of support for this study: NIH R25CA101317; NIH R25CA108731; the California Endowment; Alliance Healthcare Foundation 99–99; The Susan G. Komen Breast Cancer Foundation, San Diego Affiliate Grant Award; UCSD Academic Senate Grant; NIH 5P30CA023100; NIH U56CA92079/U56CA92081; 1U54CA132379/1U54CA132384; NIH/NCMHD 5P0MD000220; and NIH 5R25CA65745. This project was created by an educational partnership consisting of the Moores UCSD Cancer Center, Deaf Community Services of San Diego Inc., Bovee Productions, the National Association for the Deaf, and Gallaudet University. The authors would also like to thank the Deaf and hearing women who consented to be in this study, Wanda van der Vloedt, MD, for her help with database set-up and data entry, and Adrienne Kennedy, an undergraduate intern, for her assistance with this paper.

References

- Mitchell RE, Young TA, Bachleda B, Karchmer M (2006) How many people use ASL in the United States? Why estimates need updating. *Sign Lang Stud* 6(3):306–35
- Schein JD, Delk MT Jr (1974) The deaf population of the United States. National Association of the Deaf, Silver Spring
- Peterson CC, Siegal M (2000) Insights into a theory of mind from deafness and autism. *Mind Lang* 15(1):123–45
- Woolfe T, Want S, Siegal M (2002) Signposts to development: theory of mind in deaf children. *Child Dev* 73(3):768–78
- Barnett S (2002) Cross-cultural communication with patients who use American Sign Language. *Fam Med* 34(5):376–82
- Sadler GR, Huang JT, Padden CA, Elion L, Galey TA, Gunsauls DC, Brauer B (2001) Bringing healthcare information to the Deaf community. *J Cancer Educ* 16(2):105–8
- Woodroffe T, Gorenflo DW, Meador HE, Zazove P (1998) Knowledge and attitudes about AIDS among deaf and hard of hearing persons. *AIDS Care* 10(3):377–86
- Margellos-Anast H, Estarzi M, Kaufman G (2006) Cardiovascular disease knowledge among culturally deaf patients in Chicago. *Prev Med* 42(3):235–239
- Goldstein MF, Eckhardt EA, Joyner-Creamer P, Berry R, Paradise H, Cleland CM (2010) What do deaf high school students know about HIV? *AIDS Educ Prev* 22(6):523–37
- Orsi JM, Margellos-Anast H, Perlman TS, Giloth BE, Whitman S (2007) Cancer screening knowledge, attitudes, and behaviors among culturally deaf adults: implications for informed decision making. *Cancer Detect Prev* 31(6):474–9
- Zazove P, Meador HE, Reed BD, Sen A, Gorenflo DW (2009) Cancer prevention knowledge of people with profound hearing loss. *J Gen Intern Med* 24(3):320–6
- Steinberg AG, Barnett S, Meador HE, Wiggins EA, Zazove P (2006) Healthcare system accessibility: Experiences and perceptions of deaf people. *J Gen Intern Med* 21(3):260–6
- Pollard RQ, Dean RK, O'Hearn A, Haynes SL (2009) Adapting health education material for deaf audiences. *Rehabil Psychol* 54(2):232–8
- Kaskowitz SR, Nakaji MC, Clark KL, Gunsauls DC, Sadler GR (2006) Bringing prostate cancer education to deaf men. *Cancer Detect Prev* 30(5):439–48
- Folkins A, Sadler GR, Ko C, Branz P, Marsh S, Bovee M (2005) Improving the Deaf community's access to prostate and testicular cancer information: a survey study. *BMC Publ Health* 5:63
- Shabaik S, LaHousse SF, Branz P, Gandhi V, Khan AM, Sadler GR (2010) Colorectal cancer video for the Deaf community: a randomized control trial. *J Canc Educ* 25(4):518–23
- Choe S, Lim RS, Clark K, Wang R, Branz P, Sadler GR (2009) The impact of cervical cancer education for deaf women using a video educational tool employing American Sign Language, open captioning, and graphics. *J Cancer Educ* 24(1):10–15
- Sadler GR, Gunsauls DC, Huang J, Padden C, Elion L, Galey T, Brauer B, Ko CM (2001) Bringing breast cancer education to deaf women. *J Cancer Educ* 16(4):225–28
- Harry KM, Malceme VL, Branz P, Fager M, Garcia BD, Sadler GR (2012) Evaluating a skin cancer education program for the Deaf community. *J of Cancer Educ* 27(3):501–6
- Zazove P, Meador HE, Reed BD, Sen A, Gorenflo DW (2012) Effectiveness of videos improving cancer prevention knowledge in people with profound hearing loss. *J Cancer Educ* 27:327–37
- Howlader N, Noone AM, Krapcho M, Garshell J, Neyman N, Altekruse SF, Kosary CL, Yu M, Ruhl J, Tatalovich Z, Cho H, Mariotto A, Lewis DR, Chen HS, Feuer EJ, Cronin KA (eds). SEER Cancer Statistics Review, 1975–2010, National Cancer Institute. Bethesda, MD [Internet], 2012 Nov [cited 2013 Jul 21]. http://seer.cancer.gov/csr/1975_2010/
- Jemal A, Siegel R, Xu J, Ward E (2010) Cancer statistics. *CA Cancer J Clin* 60(5):277–300
- Sadler GR, Lee H, Lim RS, Fullerton J (2010) Recruitment of hard-to-reach population subgroups via adaptations of the snowball sampling strategy. *Nurs Health Sci* 12:369–374
- Jones EG, Renger R, Kang Y (2007) Self-efficacy for health-related behaviors among deaf adults. *Res Nurs Health* 30(2):185–92
- Conn VS, Hafidahl AR, Brown SA, Brown LM (2008) Meta-analysis of patient education interventions to increase physical activity among chronically ill adults. *Patient Educ Couns* 70(2):157–72
- Tamaskar P, Malia T, Stern C, Gorenflo D, Meador H, Zazove P (2000) Preventive attitudes and beliefs of deaf and hard-of-hearing individuals. *Arch Fam Med* 9(6):518–25

27. Singh J (2003) Research briefs reading grade level and readability of printed cancer education materials. *Oncol Nurs Forum* 30(5):867–870
28. Holt JA, Traxler CB, Allen TE (1997) Interpreting the Scores: A User's Guide to the 9th Edition Stanford Achievement Test for Educators of Deaf and Hard-of-Hearing Students. Gallaudet Research Institute Technical Report 97–1. Gallaudet University, Washington, DC
29. Geller MA, Downs LS, Judson PL, Ghebre R, Argenta PA, Carson LF, Jonson AL, Godfrey K, Vogel RI, Petzel SV (2010) Learning about ovarian cancer at the time of diagnosis: video versus usual care. *Gynecol Oncol* 119(2):370–5
30. Erickson W, Lee C, von Schrader S. Disability Statistics from the 2011 American Community Survey (ACS). Ithaca, NY: Cornell University Employment and Disability Institute (EDI). Retrieved Mar 11, 2013 from www.disabilitystatistics.org