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Colorectal Cancer Video for the Deaf Community: A Randomized Control Trial

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Abstract The Deaf community experiences multiple barriers to accessing cancer information. Deaf participants (n=144) were randomly assigned to view a colorectal cancer education video or another program in American Sign Language. They completed surveys pre- and post-intervention and at 2 months post-intervention. By using a crossover model, control group participants were offered the option of seeing the intervention video. The experimental group gained and retained significantly more colorectal cancer knowledge than the control group, and the control group demonstrated the greatest knowledge gain after crossing into the experimental arm. This video effectively informed the Deaf community about colorectal cancer.

Keywords ASL · Cancer prevention · Colorectal cancer · Deaf · Education

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Introduction

It is estimated that 550,000 to one million residents of the United States and Canada self-identify as members of the Deaf community [1, 2, 31]. Through their use of American Sign Language (ASL) as their preferred or sole mode of communication and their affiliation with people who share their language and culture, they are considered to be members of the Deaf community [29–30]. The capital "D" denotes this community affiliation, in contrast to deaf with a lower case "d," which is an audiologic term.

ASL, with its unique grammar and syntax, uses hand gestures, facial expressions, and body movements, that are executed and understood within a rich spatial fabric to create pictures that transmit information [3]. Being a picture based language, ASL does not directly translate into written or spoken English [3, 4] and can only be expressed visually (e.g., in person, via video, or other mediums that provide for a visual field).

Within the Deaf community, English is generally learned as a second language without benefit of aural reinforcement, if it is learned at all. This leads to lower literacy rates, reported to be at the third to fourth grade level [5, 6, 32, 33], and creates language barriers. Both outcomes impede the Deaf community's access to information and integration into the mainstream community's learning activities.

Exacerbating the Deaf community's difficulty accessing printed health information is the complexity of the health education materials themselves, which are generally written at or beyond the tenth grade level [7–9]. Direct communication between health care providers and patients is rendered less-than-optimal because few providers are competent in Deaf culture and even fewer are proficient in ASL. These barriers to communication can lead to the increased risk of miscommunication, as well as aborted communication attempts, which,

in turn, can contribute to the creation of significant disparities in the Deaf community's health knowledge and practice of health-promoting activities [8, 10–13].

Little research has been conducted on understanding the Deaf community's knowledge of colorectal cancer (CRC). Sadler, et al. found 52% of surveyed Deaf women reported no prior knowledge of CRC. A recent survey of deaf clients at Chicago's two largest Deaf-serving health care systems found that 60% of respondents aged 50 years and older reported that a doctor had ever talked to them about CRC screening and 69% rated screening as highly important [14]. An on-going relationship with a doctor was shown to increase the odds of being screened. Those who reported seeing a doctor three to five times in the past year were more likely to report that a doctor had ever talked to them about CRC screening in comparison to those who had seen a doctor zero to two times [14]. The study also found comparable screening rates for those aged 50 or older (51% had a sigmoidoscopy or colonoscopy) to the US screening rate of 48% for either test in 2002 [14, 15].

CRC was the third most common cancer and third leading cause of cancer mortality in the USA from 1999 to 2003 [16]. Recent trends reveal a decline in CRC incidence and mortality that is believed to be directly correlated with increased adherence to recommended screening guidelines. Research is needed to find ways to motivate more people to follow recommended screening guidelines to help further decrease incidence and mortality rates [16–23]. This randomized education trial tested the effectiveness of a CRC education program in ASL with open captioning and voice over that was specifically created for the Deaf community.

Materials and Methods

Hypothesis 1 Deaf adults who participate in the ASL CRC video intervention will demonstrate significant ($p \leq 0.05$) increases in general cancer and CRC knowledge than adults who do not.

Hypothesis 2 Adults who are primed with the survey questions prior to viewing the video intervention will demonstrate a significant ($p \leq 0.05$) increase in CRC knowledge and retention than those who are not.

Study Design

Colorectal Cancer: Take Action! is a 60-min, graphically enriched video created by this educational partnership. It features native ASL signers explaining how CRC develops, risk factors, screening guidelines, diagnostic and treatment methods, and the importance of clinical trials participation.

This UCSD Institutional Review Board-approved study invited Deaf adults from Southern California to "participate in a health education study." After finishing the consenting process in English and/or ASL, all participants completed a baseline survey (survey A) about socio-demographic information, general cancer, and colorectal cancer knowledge. Participants were then randomized to either the experimental arm and viewed the ASL CRC video or the control arm and received the National Cancer Institute's clinical trials PowerPoint education program: *The Basics* that was explained in ASL and English. Participants completed an immediate post-intervention survey (survey B) and a 2-month follow-up survey (survey C) with the same general cancer and colorectal cancer questions as the baseline survey.

The experimental arm participants received a copy of the video to view and share with family members and friends. Since the Deaf community has limited access to cancer information in ASL, the control arm participants were offered the opportunity to cross over into the experimental arm after completing the 2-month follow-up survey as controls.

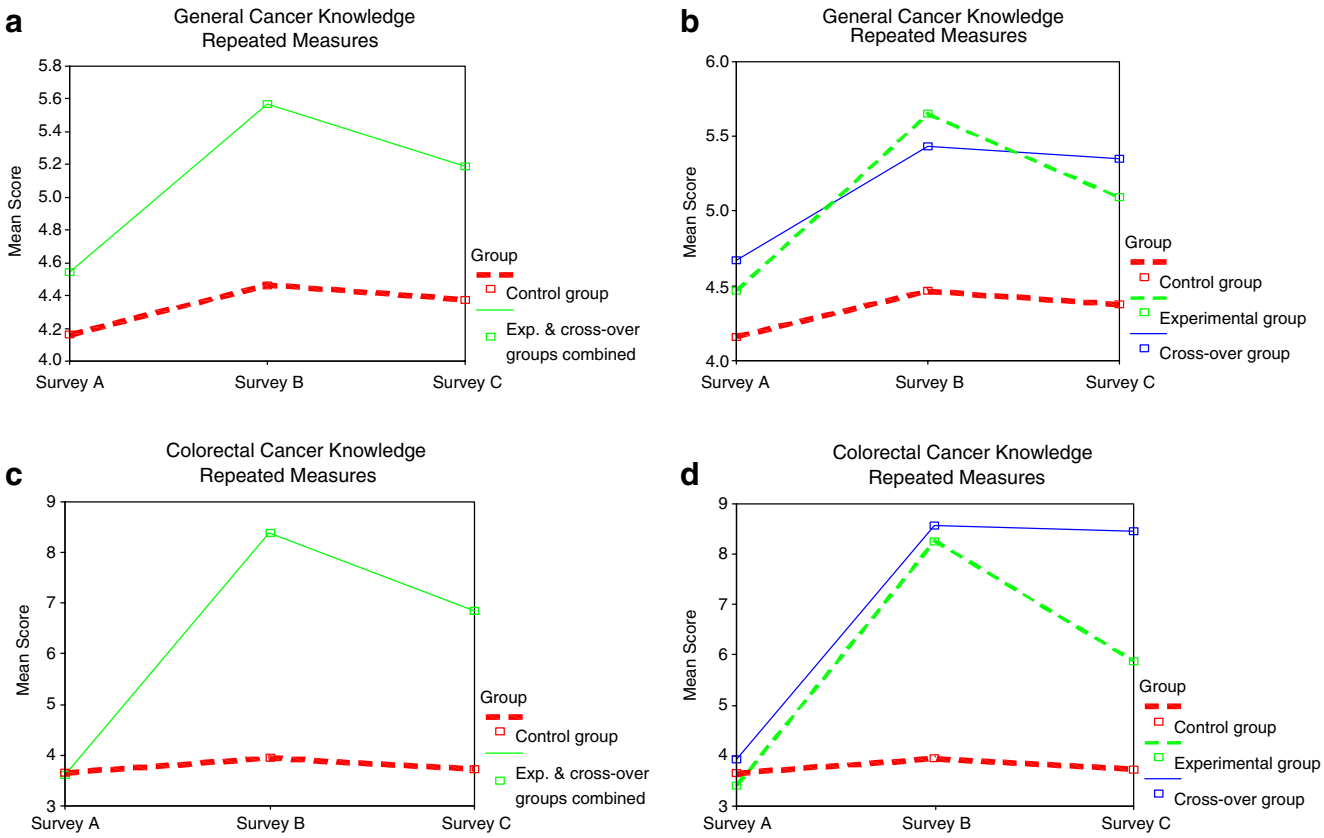
Data Analysis

All data were entered and analyzed using SPSS version 14.0 [26]. To test the study's hypotheses, general cancer and CRC knowledge scales were created based on the content of the educational video; thus, these scales have not been previously validated. The scales included seven general cancer items and 13 CRC items that were summed to create two overall sum scores: "general cancer knowledge" and "colorectal cancer knowledge." A binary coding system (1 = correct, 0 = incorrect) was used for all items. Overall continuous sum scores were created for both scales for each of the three surveys administered (i.e., survey A, B, and C). General and CRC knowledge sum scores were analyzed over time using repeated measures analysis of variance and *t* tests [24, 25]. Chi-square tests were used to compare socio-demographic and communication variables between the study arms. Multivariate models including socio-demographic independent variables were run and did not change the results, and therefore only simple repeated measures of group by general cancer knowledge and group by CRC knowledge over time are reported. It was anticipated that members of the control arm who crossed over into the experimental arm might have a baseline shift in an unforeseen way. Thus, data analysis was conducted in three ways: with original members of the experimental arm, with members of the combined experimental group including those who crossed over, and with the crossover members only. The results are reported for the combined experimental group, unless the analysis revealed a significant difference.

The power calculations planned a sample size ($n=140$) that would allow for a follow-up loss of 20% while still

being able to demonstrate statistical significance at a $p \leq 0.05$ level [27]. In reality, 144 Deaf adults participated at baseline (86 in the experimental group and 58 controls), and the 2-month retention rates were: 94.2% for the experimental arm (81/86), 86.2% for the control arm (50/58), and 64% for the crossover arm (32/50; see Fig. 1). An intent-to-treat analysis [28] was used to account those lost-to-follow-up. Generally, this is a conservative approach, but in this study using an intent-to-treat method to substitute survey C scores with survey B scores for those crossover participants lost to the 2-month follow-up may have biased results in favor of Hypothesis 2. To evaluate this, separate analyses were run to compare results without scores for those who were lost-to-follow-up (without intent-to-treat) and results with scores using intent-to-treat. Since there was no significant difference between the analyses, only intent-to-treat scores are reported.

There were 83 women and 60 men in the study, with equivalent proportions in both study arms. One third of participants [33.6% (n=48)] reported having a college degree or beyond, with no significant difference between the study arms. Most [84.4% (n=115)] defined themselves as either culturally Deaf or Deaf, 83.1% (n=118) preferred ASL as their primary method of communicating, 79.7% (n=114) reported writing notes back and forth when needing to communicate important information without an interpreter present, and 37.7% (n=52) reported usually communicating with their doctor through a sign language interpreter; no significant differences existed between the study arms for these variables. Experimental arm participants were on average 9.33 years older (M=43.5, SD=16.4, n=85) than those in the control arm (M=34.2, SD=13.6, n=58). Chi-square tests revealed differences of ethnicity and different ways of informing their doctor of a health problem between the two study arms ($p \leq 0.05$).



Note: General cancer knowledge scores range from 0-7 and colorectal cancer knowledge scores range from 0-13.
Survey A was collected at baseline, Survey B immediately following the intervention, and Survey C at two-month follow-up.
Cross-over group's Survey A scores are their Survey C scores in the control group; this includes only those 50 subjects who opted to cross-over to the experimental arm.

Fig. 1 General cancer and colorectal cancer knowledge scores. Note: General cancer knowledge scores range from 0 to 7 and colorectal cancer knowledge scores range from 0 to 13. Survey A was collected at baseline, survey B immediately following the intervention, and survey C at 2-month follow-up. Crossover group's survey A scores are their survey C scores in the control group; this includes only those 50 subjects who opted to cross over to the experimental arm

Results

At baseline, there were no significant differences between the two groups' average scores for general cancer or CRC knowledge [control group (M=4.2; M=3.7) and experimental group (M=4.5; M=3.6)]. However, there were differences in scores between kinds of knowledge at baseline, with both groups demonstrating a higher level of general cancer knowledge at baseline (experimental arm = 64.3% of questions answered correctly and control arm = 60.0% correct) then CRC knowledge (experimental arm = 27.7% correct and control arm = 28.5% correct).

This may be a reflection of the growing cancer knowledge in the community from previous cancer programs or because 26.4% (38/144) of the sample participated in a previous cancer study.

Hypothesis 1 was supported. Post-intervention, Deaf individuals who had participated in the ASL CRC video intervention demonstrated significantly ($p \leq 0.05$) higher scores when tested on CRC and general cancer knowledge than those who did not view that video. Specifically, the experimental arm demonstrated a significant increase in general cancer (M_A=4.5; M_B=5.6; M_C=5.2) and colorectal cancer (M_A=3.6; M_B=8.4; M_C=6.9) knowledge scores from point A to B ($p \leq 0.05$), with only a slight decrease (albeit statistically significant) in both average knowledge scores from survey B to C (Fig. 1a and c). Across the three points in time, the control arm demonstrated no significant change in general cancer (M_A=4.2; M_B=4.5; M_C=4.4) or CRC (M_A=3.7; M_B=3.9; M_C=3.7) knowledge scores.

In comparing the average mean change over time between arms, results showed that the experimental arm had a significant increase in general cancer (mean change = 1.04, $p \leq 0.05$) and CRC (mean change=4.8, $p \leq 0.01$) knowledge from baseline (survey A) to immediately following intervention (survey B) in comparison to the control arm (general cancer mean change = 0.26; CRC mean change = 0.23).

While there was a statistically significant decrease in CRC knowledge in the experimental group from survey B to C (mean change = −1.5) compared to the control group, the increase in knowledge from survey A to C remained statistically significant. The experimental arm had a significant increase in average CRC knowledge scores (mean change=3.2) from A to C in comparison to the control arm (mean change=0.09, $p \leq 0.01$; Fig. 1a and c). In contrast, for both groups, general cancer knowledge was unchanged from survey B to C and from A to C.

Hypothesis 2 was partially supported. Crossover participants did not have significantly higher scores from the original experimental participants for CRC knowledge immediately following the intervention (survey B), but crossover participants were significantly more likely to retain colorectal cancer knowledge at the 2-month follow-up (survey C).

The mean changes in CRC knowledge scores from survey A to B and from survey B to C for the controls after crossover did not differ significantly from the experimental group. From survey A to C, the mean change in colorectal cancer knowledge scores for the crossover arm (mean change=4.4) were significantly greater than the mean change of the original experimental arm (mean change = 2.4; Fig. 1d), thus illustrating a greater overall gain of knowledge from baseline to 2-month follow-up for the crossover group.

In fact, the original experimental participants were significantly less likely to retain their CRC knowledge from immediately post-intervention (survey B; M_B=8.3) to 2-month follow-up (survey C; M_C=5.9, $p \leq 0.05$) in comparison to the crossover arm (M_B=8.6; M_C=8.5). The mean change in general cancer knowledge scores over time (from surveys A to B, B to C, and A to C) for the crossover group did not differ significantly from the original experimental arm (Fig. 1b).

Discussion

These data demonstrate that the ASL CRC video is a viable health education tool for the Deaf community. Participants gained and retained the desired knowledge points. One possible interpretation of the better outcomes for the crossover group is that the greater retention of the video's key information points might be enhanced by giving all future viewers a set of pre-intervention questions to review (vs. learning objectives) to help them focus on the essential points of information before showing them the video. However, further research is needed since it is also possible that the participants who chose the crossover option could have been more interested in the project's topic and more focused on retaining the information presented.

While the knowledge increase was significant, the retention was not the ideal of 100%. However, this gain was accomplished with only a single viewing. Future research should also examine whether being exposed to the educational intervention more than once increases immediate and longer-term knowledge gain and retention. Future studies should also include larger sample sizes to account for the significant study attrition that occurs with a crossover design that begs an additional time commitment of participants. While this study demonstrated the video program's capacity to increase CRC knowledge, a subsequent study is warranted to determine if this video can also promote an increased uptake of screening among those individuals determined to be at higher-than-average risk of CRC.

The results also suggest that a stronger intervention impact occurred for CRC than general cancer knowledge, the probable result of the educational intervention's specific focus on CRC, with general cancer as a secondary focus.

Finally, the relatively high baseline scores for general cancer knowledge may be a direct reflection of the growing impact this multi-year program is having on Southern California's Deaf community. Malcolm Gladwell has described the occurrence of such watershed phenomena, thereby providing a theoretical framework to support the outcome of such information diffusion [34].

Conclusion

These results cumulatively provide support that the ASL-based CRC education intervention did increase knowledge. This suggests that a video-based intervention is an effective educational tool for reaching the Deaf community with cancer information.

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